DOCUMENT RESUME

ED 305 786 EC 212 586

AUTHOR Kelley-Laine, Kathleen
TITLE Disabled Youth: The Right to Adult Status.
INSTITUTION Organisation for Economic Cooperation and Development, Paris (France). Centre for Educational Research and Innovation.
SPONS AGENCY Office of Special Education and Rehabilitative Services (ED), Washington, DC.
REPORT NO ISBN-92-64-13132-9
PUB DATE 88
NOTE 65p.
AVAILABLE FROM OECD Publications and Information Centre, 2001 L St., N.W., Suite 700, Washington, DC 20036-4095 ($12.50).
PUB TYPE Reports - Descriptive (141)

EDRS PRICE MF01 Plus Postage. PC Not Available from EDRS.
DESCRIPTORS Adolescent Development; *Adult Development; *Developmental Stages; Labeling (of Persons); *Mental Retardation; *Normalization (Handicapped); *Personal Autonomy; Psychological Needs; *Self Actualization; Self Concept; Self Esteem
IDENTIFIERS *Independent Living

ABSTRACT

The concept of "adult status" for young people with disabilities is explored in terms of its social, psychological, legal, and policy implications. The report argues that traditionally institutionalized rehabilitation techniques, whether in education, vocational training, or sheltered employment, have tended not to encourage autonomy and independence and have tended to maintain disabled young people in a state of childhood. Reviewed are the stages of development in becoming an adult, such as socialization and peer groups, separation from parents, deinstitutionalization, and sexual relationships and marriage; the significance of work as the major proof of adult status; and adult status before the law. The negative consequences of labeling for the self-esteem and identity of disabled persons are explored, along with methods for meeting special needs without the burden of negative labels. Three examples are described where the development of adult status is a central concern: (1) a specialized team of social workers, vocational training teachers, and a psychiatrist in Genova, Italy, work to train mentally disabled individuals for competitive employment; (2) individual counseling of an adolescent with Down Syndrome, helps her attain adult living and independence; and (3) mentally retarded young people are informed about the nature of their disability. (JDD)

****
* Reproductions supplied by EDRS are the best that can be made *
* from the original document. *
****

ED305786

U.S. DEPARTMENT OF EDUCATION
Office of Educational Research and Improvement
EDUCATIONAL RESOURCES INFORMATION CENTER (ERIC)

☑ This document has been reproduced as received from the person or organization originating it.

☐ Minor changes have been made to improve reproduction quality.

• Points of view or opinions stated in this document do not necessarily represent official OERI position or policy.

EC 212586

"PERMISSION TO REPRODUCE THIS MATERIAL IN MICROFICHE ONLY HAS BEEN GRANTED BY

J R West

TO THE EDUCATIONAL RESOURCES INFORMATION CENTER (ERIC)."

EC

Centre for Educational Research and Innovation (CERI)

DISABLED YOUTH

THE RIGHT TO ADULT STATUS

ORGANISATION FOR ECONOMIC CO-OPERATION AND DEVELOPMENT

Pursuant to article 1 of the Convention signed in Paris on 14th December, 1960, and which came into force on 30th September, 1961, the Organisation for Economic Co-operation and Development (OECD) shall promote policies designed:

- to achieve the highest sustainable economic growth and employment and a rising standard of living in Member countries, while maintaining financial stability, and thus to contribute to the development of the world economy;
- to contribute to sound economic expansion in Member as well as non-member countries in the process of economic development; and
- to contribute to the expansion of world trade on a multilateral, non-discriminatory basis in accordance with international obligations.

The original Member countries of the OECD are Austria, Belgium, Canada, Denmark, France, the Federal Republic of Germany, Greece, Iceland, Ireland, Italy, Luxembourg, the Netherlands, Norway, Portugal, Spain, Sweden, Switzerland, Turkey, the United Kingdom and the United States. The following countries became Members subsequently through accession at the dates indicated hereafter: Japan (28th April, 1964), Finland (28th January, 1969), Australia (7th June, 1971) and New Zealand (29th May, 1973).

The Socialist Federal Republic of Yugoslavia takes part in some of the work of the OECD (agreement of 28th October, 1961).

The Centre for Educational Research and Innovation was created in June 1968 by the Council of the Organisation for Economic Co-operation and Development for an initial period of three years, with the help of grants from the Ford Foundation and the Royal Dutch Shell Group of Companies. Since May 1971, the Council has periodically extended the mandate, which now expires on 31st December 1991.

The main objectives of the Centre are as follows:

- *to promote and support the development of research activities in education and undertake such research activities where appropriate;*
- *to promote and support pilot experiments with a view to introducing and testing innovations in the educational system;*
- *to promote the development of co-operation between Member countries in the field of educational research and innovation.*

The Centre functions within the Organisation for Economic Co-operation and Development in accordance with the decisions of the Council of the Organisation, under the authority of the Secretary-General. It is supervised by a Governing Board composed of one national expert in its field of competence from each of the countries participating in its programme of work.

Publié en français sous le titre :

LES JEUNES HANDICAPÉS
LE DROIT AU STATUT D'ADULTE

© OECD, 1988
Application for permission to reproduce or translate
all or part of this publication should be made to:
Head of Publications Service, OECD
2, rue André-Pascal, 75775 PARIS CEDEX 16, France.

Cover photo: Association des Paralysés de France

This report was prepared within the framework of the CERI project on Active Life for Youth with Disabilities. The Centre began working on the issues of education and transition to adult and working life for disabled young people in 1978. A number of reports have been published, summarising the results of this major international project.

The present phase of the work has specifically concentrated on questions of becoming an adult; a report entitled *Young People with Handicaps, the Road to Adulthood*, published in 1968, reviewed transition programmes and described major innovations in Member countries. This volume, published on the responsibility of the Secretary-General, has been prepared by Kathleen Kelley-Lainé, a member of the Secretariat in co-operation with experts from many OECD countries. Taking the extensive international information emerging from the project, the concept of "adult status" is explored in terms of its social, psychological, legal and policy implications, with the purpose of informing those responsible for supporting young people with disabilities of how services and professionals can favour and facilitate development towards adult status.

Autonomy, responsibility and risk-taking, necessary elements for becoming an adult, are not always considered to be essential stepping stones in the lives of these young people, and are often overridden by protective lifelong support systems that tend to maintain them in a state of "eternal childhood". The report outlines some basic concepts regarding disability, handicap and becoming an adult and describes on-going practices in Member countries that are particularly sensitive to these developmental issues.

This study, like the previous ones, would not have been possible without the generous assistance, in the form of a grant, from the United States Department of Education, Office of Special Education and Rehabilitative Services.

Also Available

THE EDUCATION OF THE HANDICAPPED ADOLESCENT:

YOUNG PEOPLE WITH HANDICAPS. The Road to Adulthood (January 1987)
(96 87 01 1) ISBN 92-64-12903-0 60 pages £6.50 US$13.00 F65.00 DM29.00

INTEGRATION OF THE HANDICAPPED IN SECONDARY SCHOOLS. Five Case Studies (November 1985)
(96 85 03 1) ISBN 92-64-12774-7 168 pages £8.00 US$16.00 F80.00 DM36.00

HANDICAPPED YOUTH AT WORK. Personal Experiences of School-Leavers (July 1985)
(96 85 02 1) ISBN 92-64-12708-9 84 pages £5.50 US$11.00 F55.00 DM25.00

THE TRANSITION FROM SCHOOL TO WORKING LIFE (July 1983)
(96 83 02 1) ISBN 92-64-12438-1 192 pages £7.40 US$15.00 F74.00 DM33.00

INTEGRATION IN THE SCHOOL (August 1981)
(96 81 02 1) ISBN 92-64-1222-X 150 pages £3.80 US$8.50 F38.00 DM19.00

Price charged at the OECD Bookshop.

THE OECD CATALOGUE OF PUBLICATIONS and supplements will be sent free of charge on request addressed either to OECD Publications Service, Sales and Distribution Division, 2, rue André-Pascal, 75775 PARIS CEDEX 16, or to the OECD Sales Agent in your country.

CONTENTS

I. INTRODUCTION 7

Policy and Philosophy 8

II. THE SOCIAL CONSTRUCTION OF DISABILITY 11

1. The Role of Handicap in a Taken-for-Granted World 11
2. The Social Construction of Identity 13
3. Learning to be Disabled 16

III. BECOMING AN ADULT 22

1. Stages of Development 22
2. The Significance of Work 26
3. Adult Status Before the Law 29

IV. TOWARDS A SUBJECT-ORIENTED APPROACH 32

1. Handling the Dilemmas of Labelling 32
2. Alternative Solutions and Self-definition 33
3. Self-definition and Independent Living 37

V. PRINCIPLES INTO PRACTICE 43

1. The Genova Challenge – Adult Status through Work for Mentally Handicapped Youth 43
2. Individual Case Management as a Support for Personal Growth Towards Adulthood 47
3. Coming to Terms with Identity as a Disabled Person 49

VI. CONCLUSIONS 55

Policy Implications for Adult Status 55

Notes and References 59

I. INTRODUCTION

The last ten years have witnessed fundamental changes in policy and practice concerning the education and support of disabled young people from childhood to adult life. All Member countries have been involved in revising past legislation to some degree, and traditional segregative practices are increasingly moving towards integrating young people with disabilities in school, work and in the community at large.

The Centre for Educational Research and Innovation (CERI), within the framework of the Project on The Education of the Handicapped Adolescent, has studied these changes, first by concentrating on the question of schooling and then on the issue of transition from school to adult life. Reviews of recent policies and innovative practices have taken place in a number of Member countries. Five published reports and a considerable number of technical papers, already available, summarise the information gathered by the Secretariat[1].

The international nature of the work and the involvement of a large number of Member countries has been very rich in the diversity of data produced, and has revealed rather clearly the different historical and theoretical traditions that have informed and continue to influence rehabilitative and educational strategies in this field. The ways in which people with disabilities are classified and the definition given to the notion of "handicap" are important factors in determining the destinies of people bearing these labels. A monograph entitled "Disability and Restricted Opportunity" was issued by CERI in June 1987. The paper attempts to clarify the terms "handicap" and "disability" and show how the concepts may change as a person moves from childhood to adult and working life[2].

Such latent, underlying questions of definition, of how society actually views people with disabilities, and how such social representations influence the lives of people, have not been given sufficient attention. It is surprising to note how relatively little interest social scientists have given to the field of disability in the past, and how much this area has remained the guarded domain of medical personnel and other practitioners. The result is that social policies have not been significantly influenced, as compared to other areas such as youth problems, immigrants, family, etc., by the analysis of underlying social and psychological factors.

There exist a number of hypotheses on why this has been the case, some of the most interesting ones are those forwarded by persons with disabilities in the social science field. One explanation is that disability has been considered (by the "able-bodied" world) as a personal tragedy, a biological, physical fact that calls for aid and support. Therefore, the "social service", rehabilitative approach, identifying and fulfilling "special" needs has dominated policies and practices. People with disabilities have therefore been considered as the passive consumers of these services. For many members of the DPI (Disabled Peoples' International) movement, this has been a form of social oppression, keeping persons with disabilities in a state of "eternal childhood".

The concept of "adult status" is therefore, in its practical, political and theoretical implications, rich as a tool for analysing social phenomena likely to influence policies and practices. It is not an easy task to link social and psychological issues to policy-making. This report tries to take up what may be an impossible challenge, by describing, without of course doing justice to, some of the social and psychological issues seen as influencing the attainment of "adult status" for young people with disabilities. The report is not a statement on the "causes" of disability, and it does not go into, nor attempt to analyse, the important economic and social structural aspects of the "production" of disability within our present industrial societies. For some, this may be the report's main drawback.

The concept of "adult status" is proposed as an analytical tool because of the various levels of meaning it contains. Status according to the dictionary implies social or professional position, condition or standing to which varying degrees of responsibility, privilege and esteem are attached; it also implies a high position, prestige; the legal standing or condition of a person. The concept applied to young people with disabilities poses the problem of their position, prestige and responsibilities in society, as well as the question of social and personal esteem, and legal adult rights.

The acquisition of "adult status" is a complex and problematic issue for many young people. For those with disabilities it is often made difficult by attitudes linking disability, dependence and eternal childhood. Public opinion tends to consider "disability" as a generalising concept, and the attempt made to construct a classification system that would facilitate the distribution of services according to easily identifiable categories has contributed to erroneous thinking about what persons with certain disabilities can or cannot do. The degrees of dependence, independence, need of aid, etc., are as variable as are individuals. "Adult status" may be considered as an ideal goal that individuals may more or less reach; persons with disabilities are no exception – however, they must be given the legal right to work towards that goal.

One may say today that integration is one road toward the goal of "adult status"; there are other roads yet to be explored. This report tries to suggest some of these, albeit in an exploratory way.

Policy and Philosophy

Although integration has become a widely accepted policy in most Member countries, the translation of this policy into practice is variable both in terms of the rapidity of the process and the forms it takes. In order to fully understand the differences in the way the policy of integration is applied in Member countries, one needs to examine the kinds of philosophies that have been dominant in the system, as well as the strength of the institutional tradition.

It is well known that the medical model has had a significant effect in the field of disability. The image of "handicap" has been closely linked with that of illness and, therefore, has led to the creation of a strong rehabilitation system that has been very difficult to change, especially due to the vested interest of a wide array of professionals in the survival of the system. In countries where the medical tradition has had the strongest impact, new legislation promoting a more integrative approach tends to be interpreted in traditional ways. Although special, separate institutions are diminishing, integrative measures tend to continue to be interpreted as more or less separate from the ordinary school or workplace. One sees the growth of special classes, units or enclaves within the normal system. This strategy guarantees the specific role of specialised personnel; even though increasingly the tendency is to envisage the redefinition of professional roles as supportive ones such as the use of interdisciplinary

teams which enable the continued use of expertise, but make it available for maintaining the disabled person within the normal system.

In a number of countries, a wave of social criticism emerged in the late 1960s and early 1970s which included disabled people within an analysis of the segregative effects of the social system. The notion of "handicap" was not so much considered as an "anomaly" or "illness" of the individual, but as the result of the interaction of a person different from the average within a social system not tolerant of the difference. Not only disabled persons, but other marginalised and disadvantaged groups, such as immigrants, deviants, drug addicts, etc., were seen to share similar difficulties. Close social analysis revealed the inequalities in power relationships between those who did and those who did not fit into the system. Attempts at changing the system to make it more equal were made through significant legislations based on human and equal rights. Concerning disabled persons, laws stipulating the right to education in the mainstream, the right to employment, the right to live in non-restrictive neighbourhoods, etc., were created. These laws were not so much addressed at improving the efficiency of the system as making fundamental changes that could be applied. Therefore, in some countries, the law included practical conditions for its application, such as stipulating that no more than two disabled children could be integrated in a class; that integrated schools must have support staff, etc. In some places, pressure groups, parents and voluntary associations were able to force institutions to apply the laws.

After almost a decade of reforms, new legislation, and measures improving the system in order to make integration a reality, it is becoming increasingly evident that some of the most important barriers remaining, despite administrative reforms, are of a more subjective, social/psychological nature. These are, of course, the most difficult to overcome as they cannot be managed directly by policy measures, although they may be directly linked.

Evidence that policy makers and administrators are increasingly concerned with this dimension was provided at the High Level Conference on Active Life for Handicapped Youth held in December 1986 at the OECD. One Minister called for a new constructive definition of handicap based on the perspective of the individual's situation. He said that more attention needs to be paid to the social situation and the psycho/social situation of disabled youth.

Another stated that the greatest barriers in the system are attitudes – blinkers that have been inherited from the past – and insisted that disabled people are the ones who need to be most involved in decisions concerning their lives and judgements about the effectiveness of programmes. Also discussed was the creation of an environment in which self-esteem and independence could be developed. This calls for sufficient empathy with disabled youth to understand their psychological needs as well as their physical ones. Stress was put on the importance of risks and challenges to build up one's self-image and consolidate one's identity.

Transition to adulthood means the building up of an adult identity, confidence that one is competent and can survive without the parental support that was necessary as a child. The move from childhood to adult status can be defined as the gradual process of building up self-esteem and confidence in one's capacity to stand on one's own; to be able to solicit the support when necessary, but not live under it permanently as in childhood. This process is a difficult one for all young people, but is made even more so for those with disabilities because of obvious material and practical reasons, and perhaps even more for social and psychological ones.

This report will examine some of the social and psychological barriers to gaining adult status that young people with disabilities have to face. It will try to do so with an underlying concern of how administrators and policy makers can become sensitive to these issues and translate their implications into effective practice.

Working with the subjective needs of disabled youth is perhaps the most difficult task for professionals and administrators to take on as it implies facing up to deeply rooted attitudes based on uncontrolled prejudice and fears in everyone. Concern with the individual and subjective needs of disabled youth means being able to identify with them as persons and not just managing their lives as "categories to be rehabilitated".

However, the fact of labelling and placing people in administrative categories to segregate them in separate institutions has been based on an underlying need to dis-identify with the differences and disabilities that provoke the fear of becoming disabled oneself as well as the fear of being rejected because one is different from others. For persons living within such an environment of psychological rejection, even the best services cannot help them build up the self-esteem necessary to lead an adult and independent life.

An approach that addresses questions of identity is the most difficult in all countries. It cannot be legislated, it cannot be serviced, but depends on a full understanding of the fear of difference and the insecurity in everyone, especially those working with disabled people. It is translated, in practical terms, by restituting human rights and adult status, and by allowing and helping disabled citizens to have a real role in society[3].

II. THE SOCIAL CONSTRUCTION OF DISABILITY

1. The Role of Handicap in a Taken-for-Granted World

In order to fully understand the handicapping effects of being classified or labelled as "handicapped", there needs to be a subjective comprehension of the moral status of persons bearing such labels. Subjective comprehension means being able to identify with a person as "subject" and consider him/her as a complex human being. As pointed out above, the medical model with its labelling and classificatory approach does not promote subjective comprehension but rather tends to simplify and objectify its clients for operational reasons.

An attempt will be made here to explore the reality of "handicap" through a subjective approach and to try to examine some of the mechanisms at work in the negative consequences of being labelled as different from others.

All societies, cultures and social groups have taken-for-granted assumptions of what is to be defined as "normal" behaviour, thought, language and appearance. Even though these conceptions of normality are socially constructed and therefore relative and variable, they are no more questioned as to their objective reality than the air one breathes. These assumptions converge to make up the "real" world, a tacit convention of expectations that rule all behaviour. Anything that differs from these expectations is to some degree or another considered as unusual, different or deviant; meeting the unexpected is often likely to place the individual in a difficult, uneasy position, that is, upset his usual behaviours which are taken for granted and therefore are carried out automatically without conscious thought.

Being disabled makes one stand out from the usual taken for granted reality as it brings to the attention of the observer routine, automatic gestures. It causes tension, insecurity and doubt among all concerned. Because the taken for granted daily world is like a common language shared by all, both those with disability and those without feel the strain in such encounters.

Comer and Piliavin, two American social psychologists, carried out experimental research on the effects of physical difference on face-to-face interaction. They report that both partners in these encounters felt ill at ease in different ways and for different reasons:

> "Physically normal persons often report definite feelings of uncomfortableness and uncertainty when interacting with persons who have some physical handicap. When Kleck, Ono and Hastorf (1966) had able-bodied subjects interact with an apparently handicapped confederate, the behavioural output of the subjects was stereotyped, inhibited and overcontrolled, as compared to other subjects interacting with the same confederate appearing physically normal. The subjects who talked to the handicapped individual terminated the interaction sooner, distorted their expressed opinions and

tended to demonstrate less variability in their behaviour. Kleck also reported greater motoric inhibition by normal subjects in the presence of the handicapped confederate".[4]

The American sociologist, Erving Goffman, in his now classical work on "Stigma" tried to minutely analyse the processes at work when a person with a "difference", be it a disability or other type of "deviation" from the "expected", stands out from the usual, unattended reality[5]:

"In all these various instances of stigma, an individual who might have been received easily in ordinary social intercourse possesses a trait that can obtrude itself upon attention and turn those of us whom he meets away from him, breaking the claim that his other attributes have had on us. He possesses a stigma, an undenied differentness from what we had anticipated. We and those who do not depart negatively from the particular expectations at issue, I shall call 'normals'."

An impairment, then, is a sign indicating that an alternate reality is at hand and that different behaviours are called for. The reasons for behaving differently are often thought to be necessary in that situation but are in fact due to the insecurity provoked by the difference.

"Standing out" from the "normal" everyday reality, then, has connotations of inferior status, inability to do and be as others. This has significant repercussions on the person's self-concept, and the negative self-image in turn influences the reactions of others. A young woman with a physical disability writes:

"When I began to walk out alone in the streets of our town ... I found then that wherever I had to pass three or four children together on the sidewalk, if I happened to be alone, they would shout at me. ... Sometimes they even ran after me, shouting and jeering. This was something I didn't know how to face, and it seemed as if I couldn't bear it. ... One day I suddenly realised that I had become so self-conscious and afraid of all strange children that, like animals, they knew I was afraid so that even the mildest and most amiable of them were automatically prompted to derision by my own shrinking and dread."[6]

The visibility of signs of an impairment or of a particular difference influences the reactions of others to the person. Goffman, in his book, says that the visibility of stigma must be distinguished from whether people have previous knowledge about it before meeting the individual. Another distinction is obtrusiveness – how much it interferes with the flow of interaction:

"At a business meeting, a participant in a wheelchair is certainly seen to be in a wheelchair, but around the conference table his failing can become relatively easy to disattend. On the other hand, a participant with a speech impediment, who in many ways is much less handicapped than someone in a wheelchair, can hardly open his mouth without destroying any unconcern that may have arisen concerning his failing, and he will continue to introduce uneasiness each time thereafter that he speaks."[7]

Disabilities of a mental nature, such as mental retardation or mental illness are not visible and may cause more tension and insecurity than any visible difference. It is usually through the non-conformity of taken-for-granted communication patterns that mental illness or mental retardation are perceived. Unsuccessful socialisation can be the cause of these breaches of etiquette as in the case of institutionalised children who have missed out on the usual life sequences that others go through, for example, not being able to use a bus alone or order a meal in a restaurant because one has never had the experience of doing so. The lack of

independence and social know-how is not due to the initial impairment but rather to the lack of sufficient socialisation.

The reaction is often to reject the individual as a human being (as this example, related by a young mentally retarded man, shows):

> "Some people always tease 'bout us mentally retarded guys. Why don't you stop and think about it. Mentally retarded is something handicapped inside your brain. I have a little trouble learning. If you stop and think about what you're doing, you're hurting yourself. I love to play sports, just like anybody else – like any normal kids. I'm a nice guy. I laugh at some things."[8]

Reactions may also be patronisingly kind, but still relegating those outside the norms of taken-for-granted behaviour to the "subnormal world" – often that of animals:

> "Sometimes it's pathetic the way these retarded people eat up anything nice you say about them. They're like puppy dogs. They'll lap up affection as long as you can give it out. I've had half a dozen of these Pacific people work for me over the years and they've had such a need to be loved – I guess you could say – that it's hard to deal with them. You've got to give them attention and affection every minute or you disapppoint them terribly. It's the price you've got to pay if you're going to have them around. You've got to give them love every minute and you've got to mean it. I can do it because I do like them and they know it."[9]

2. The Social Construction of Identity

It is generally agreed that self-concept is learned and that it represents a dynamic factor in behaviour and becomes an integral part of one's identity. Self-concept also implies learned anticipations of being accepted or rejected in specific situations.

The concepts of "self", "self-image", and self-esteem as administrative tools, are not easily compatible with the labelling approach in terms of policy development. Labelling implies obtaining knowledge of a given population by identifying symptomatic similarities and brushing individual differences by the wayside. The danger is, of course, that the individual differences recur and develop into manifest dysfunctions sabotaging a given policy measure.

A more "subject" oriented policy is able to accommodate individual differences and anomalies and, in fact, makes these the centre of concern when drawing up strategies to deal with disablement. Interest in such concepts as "self", "self-image" and "self-esteem" is therefore an important element in the reflection of the role that these aspects of identity actually play in disablement.

Identity building begins at birth when the first self-image of the child is reflected in the mother's face – it is the first recognition that the child exists as a living, human being. This reflection continues and the accumulated self-images weave together to constitute the individual's sense of identity. The power of this first "recognition" is not to be underestimated and gives some idea of the infantile origins of the much-feared estrangement or "loss of face". In order to become a person with a stable sense of identity presupposes a basic trust in one's origins – and the courage to emerge from them. The key problem of identity, then, is the capacity of the person to maintain a continual sense of self despite inner and outer changes in the course of life. Becoming an adult, then, is strongly linked to this feeling of a positive identity and the self-esteem that has been built up through esteem by important persons like parents, siblings, friends, etc.

Growing into an adult human being, therefore, is a social enterprise involving many actors, some of whom have a primary influence on the self-image and identity of the individual such as parents and family and others who build on and carry further these fundamental acquisitions in a more secondary way through schooling and other social institutions. In the process of becoming an adult member of society, the child adopts the subjective notions his parents have of both him and society and takes them as being "real". It is through the strong, emotional overtones of this "primary socialisation" that the child acquires an "objective" notion of reality, as well as a sense of who he is. The child comes to see himself as others see him and by this process comes to understand his fellow men, and to see the world as a meaningful social reality.

The acquisition of language helps to make the roles and attitudes learned within the home widely applicable outside through a shared common framework, thus giving them an even greater sense of general, unquestioned reality. The individual is confronted by different social groups and moves from "primary" to "secondary" relationships.

Secondary socialisation is the process by which individuals enter into social "sub-worlds" and, in most societies, social rituals accompany the transition from primary to secondary socialisation. Secondary socialisation implies the acquisition of role-specific knowledge and entails subjective identification with the role and its appropriate norms. It also depends on an already-formed "self" and whatever new contents are now internalised must somehow be superimposed upon an already-present reality. There is, therefore, a problem of consistency between the original and the new roles and norms to be adopted. For disabled youth, this may be a particularly difficult transition to make and will be discussed in detail later on.

While primary socialisation cannot take place without an emotionally-charged identification of the child with his parents, secondary socialisation can dispense with this kind of identification and proceed effectively with only the amount of mutual identification that enters into any communication between human beings. As will be seen in the next section, for candidates of "exceptional" treatment such as disabled people, the emotionally-charged overtones of primary socialisation follow through to secondary institutions. The "total care" policy that caters to meeting "special needs" often cannot leave the personal worlds of inmates unattended. Once an individual is placed within the category of being "cared for", the primary tones of socialisation cannot be completely eliminated and the status of "child" as opposed to "adult" remains close at hand.

Secondary socialisation is the initiation of the individual into the social world where, through the acquisition of roles, responsibilities and rights, he comes to know the place he holds in society. The world of secondary socialisation, because it is a more formal, anonymous world containing less of the emotional involvement of primary socialisation, makes it possible to detach a part of the self as relevant to role-specific situations. The individual then establishes distance between his total self and its reality on the one hand and the role-specific partial self and its reality on the other. This important feat is possible only after primary socialisation has taken place. It is easier for the child to "hide" from his teacher than from his mother (not so evident for the disabled, totally institutionalised child). Conversely, it is possible to say that the development of this capacity to "hide" is an important aspect of the process of growing into adulthood.

Being an adult is having established a personal world of subjective meanings through primary socialisation and with this background, internalising role-specific meanings through secondary socialisation. The reality accent of knowledge internalised in primary socialisation is given almost automatically. In secondary socialisation, it must be reinforced by specific pedagogic techniques, "brought home" to the individual. The more these techniques correspond to the person's subjective experiences and represent continuity between the

original and the new element of knowledge, the more readily they acquire the accent of reality.

For young people who have been labelled "handicapped" from birth, secondary socialisaton will build on this primary knowledge. Pedagogic techniques, especially adapted to a certain impairment, although they are intended to correct or compensate for the impairment, often serve to reinforce it. Roles become imbedded with negative meanings. Special status in society means the acquisition of a "special" reality.

Secondary socialisation may take on the affective intensity of primary socialisation when the process requires an actual transformation of the individual's "home" reality. The relationship of the individual to the socialising personnel becomes correspondingly charged with "significance", that is, the socialising personnel take on the character of "family" *vis-a-vis* the individual being socialised. Autobiographical testimonies of disabled persons often describe the strong emotional relationships encountered with a teacher, nurse, or an understanding colleague who has helped them enter the "normal" world. Helen Keller's passionate relationship with her teacher comes to mind.

Institutions for disabled people, especially those with mental handicaps and psychotic disorders, are often permeated with affective intensity – for both staff and clients. Visitors from the "outside" are usually surprised by the intimate behaviour, normally reserved for family situations, that are engaged in by inmates. Although this kind of behaviour may be considered as part of everyday reality with primary relationships, within institutional, secondary contexts, it is considered as threatening. People institutionalised for long periods of time and who carry with them to the outside such behaviours that were an integral part of "institutional reality" are considered as deviant and need to be "re-socialised" in order to function in society.

Not only the acquisition, but also the maintenance of "adult identity" is an ongoing social process embodied in the routines of everyday life in the individual's interaction with others. Identity is confirmed daily through casual contacts, as well as supported emotionally by family and friends. This assumes that the individual feels positive about the identity being confirmed. The same process pertains to the confirmation of identities that the individual may not like. Even casual acquaintances may confirm his self-identification as a hopeless failure; but when a wife, children and secretary ratify this, it is with undeniable finality. A number of "identity management" techniques are used to maintain, or re-establish, one's self-image and others are used when this is not possible. Social science literature is rich in examples of how those with "deviant" or "spoiled identity" manage their image in social situations. The problems posed for disabled youth by "identity management" will be discussed in the next section. It needs to be mentioned here that identity management concerns the confirmation, maintenance or denial of subjective reality. The actors, both primary and secondary, provide the background against which the individual stages his identifications.

Some people maintain that adolescence is a relatively recent invention and has become amplified in modern industrial societies. The social and economic dimensions of this argument will not be examined here, rather we will discuss the important psychological and social role played by "adolescence" in the transition to adulthood.

Transition implies process and movement from one point to another. Adolescence is the period of transition when one is no longer a child, and not yet an adult. It is an essential moment of trying out new roles, and still being able to go back to old ones. Those working with adolescents often remark that they can act like infants, with the same intense demands for attention and affection. Adolescence is not only the concern of the young person, it is also an important period of transition for parents. It is not only the young person who is suddenly surprised to find himself in a fully grown, adult body. The need to become accustomed to the

adult body of their child is not an easy task for parents. The challenge of emerging sexuality is something that many parents are not sufficiently prepared to meet.

Adolescence is a time of initiation, when society is able to symbolically mark the end of childhood and the entry into adult status and adult roles. Anthropologists have studied the important function of the symbolic action of initiation rites in primitive societies. Much has been written concerning the necessity of initiation for the social cohesion of the group and the transmission of values, norms and adult identity. Such symbolic rituals also serve to alleviate the particular psychological conflicts especially acute during this period of life.

In modern societies such initiation rites are gradually disappearing whilst the period of adolescence is prolonged. Some people attribute the increasing malaise among young people, especially the generalisation of the drug problem, as an expression of this lack of clear limits, and role definition concerning the adult identity young people have to look forward to. Until recent years, getting a job was the major criterion for stepping into an adult identity. Today, the considerable difficulties young people have in finding a job reduces this major factor of role definition.

For young people with disabilities the period of adolescence presents the question of being allowed to be "adolescent". Parents and institutions tend to be over protective of young people, especially since growing up presents itself as an even more dangerous enterprise than for those who are not disabled. For those with more severe disabilities, and high levels of dependence, parents and professionals may even tend to ignore adolescence altogether and continue to treat the person as a child; confrontation with "dangerous" or risky situations is eliminated by all sorts of protective personal, social and physical barriers, both on the part of parents as well as professionals. One of the most important barriers is the separate, specialised institutional frameworks that have been set up to "care for" and enclose people with disabilities.

3. Learning to be Disabled

If then identity, "self-concept" and "self-esteem" are socially constructed and based on relationships with other people (parents, peers, adults, etc.) then the process of labelling is a significant contributor to learning to be disabled.

> "The question, 'What is it really? What is its right name?' is a nonsense question ... one that is not capable of being answered. ... The individual object or event we are naming, of course, has no name and belongs to no class until we put it in one. ... What we call things and where we draw the line between one class of things and another depend upon the interest we have and the purposes of the classification."[10]

It has already been argued that, although the declared goal of formal labelling and placing people into categories is to enable services and monies to be provided for special needs, the latent consequences for people to whom they are applied may be negative.

Because labels reinforce the fact of "standing out" from the taken-for-granted world, they restrict life chances, curtail the freedom of the individual, in their access to society's institutions and discredit their self-image as a low status, discounted person. These secondary consequences in turn produce deviant effects which are treated by society as if they were due to the original primary impairment. This process is known as the "self-fulfilling prophecy".

Once a formal label has been applied, the individual learns how to live up to the expectations of his new status. This is particularly evident when the label leads to institutionalisation. Robert Scott writes in *The Making of Blind Men:*

"When those who have been screened into blindness agencies enter them, they may not be able to see at all or they may have serious difficulties with their vision. When they have been rehabilitated, they are all blind men. They have learned the attitudes and behaviour patterns that professional blindness workers believe blind people should have. In the intensive face-to-face relationship between blindness workers and clients that make up the rehabilitation process, the blind person is rewarded for adopting a view of himself that is consistent with his rehabilitator's view of him and punished for clinging to other self-conceptions. He is told that he is 'insightful' when he comes to describe his problems as his rehabilitators view them, and he is said to be 'blocking' or 'resistant' when he does not. Indeed, passage through the blindness system is determined in part by his willingness to adopt the expert's view about self."[11]

Labels are not only formally set and applied in institutions. Informal labelling occurs in the family, peer groups, etc. and affects primary socialisaton. Although they may not have the formal repercussions that formal labelling does (i.e. institutionalisation), the consequences of informal labelling can have significant restrictive effects, especially when the category of impairment is highly stereotyped, like mental retardation.

Learning to be disabled often begins even before formal labels are actually administered. As mentioned in the previous section, identity construction begins at birth. Here are some concrete examples taken from disabled persons' own words:

"When a cripple comes into the world, the stage on which he will have to act his part in life is already set by people's attitude towards the disabled. Maybe it is not so strange, then, that the very first question a mother usually asks, when she has given birth to her child, is not whether it is alive, but if it is well-formed."

"It may seem strange, but during my childhood, I very often wondered what my mother felt when she realised that she had given birth to a cripple. I cannot remember that I ever dared to ask her directly about it. Although I had no reason to fear the answer, I must have been afraid of rejection, afraid that she would have admitted disappointment or that hesitation in her eyes would have betrayed just what I feared most: bitter repulsion."

"Now, I am sorry that I did not dare to ask her, because I know that her answer would have saved me from many horrible thoughts. ... It was not until I was about eight or nine years of age that I realised that neither my mother nor anyone else could have suspected anything at the time when I was born. Later on, however, my parents were puzzled when I did not move the way other children did and so asked a doctor about me. What they felt when they fully realised that I suffered from cerebral palsy, I do not know, but I should think that it must have been as if a world had tumbled down."

"A new world had to be built: a world of limitation, but not that of resignation: a world of hopes and determination, but not that of despair. And yet, even if the inner world, our world, could be adjusted, the outer world had to be faced as it was, and a new life – my life – started being formed through the meeting of these two worlds."[12]

When babies are born with an impairment, the "outer world", usually in the form of doctors and medical staff, have a determinant influence on the mother and child and how both will deal with disability later on. As representatives of "outside" social attitudes, they either reinforce the fear, guilt and shame involved with having a baby "not like the others", or may bring about fundamental changes in parental attitudes through a sympathetic, helpful approach.

In a case where the parents' dismay was dealt with in a sensitive way by the pediatrician the mother said:

"I told the pediatrician not to let the baby live, I didn't want it at first, but he gave me lots of information and made me more aware ... he made me want him."

In a separate interview her husband confirmed a similar reaction:

"We didn't accept him for the first two days, we just hoped he'd die, we knew little about it. It was the pediatrician who first convinced us that the baby was ours... The hospital staff was also fantastic."[13]

However, most parents meet with insensitive attitudes and feel that their emotions are totally disregarded. They see the informant as being distant, non-caring, unable to relate to them and insensitive to the stresses they are facing:

"Doctors aren't interested in feelings: he told me to let her go into an institution to let her die. They wouldn't let me touch her for four and a half months."

"The doctor said my child is a 'mongoloid' and I should send her to an institution. He just kept looking above me, as if I wasn't there."

"The pediatrician didn't know how to relate to us. He spoke so softly that I couldn't hear him ... I didn't understand him and blamed myself for giving my child the virus."

(One woman who spoke little English):

"The doctor kept talking about 'mongol' and I thought he said that my baby was a mongrel, you know, a dog. I wasn't allowed to see her for 24 hours, and I wasn't allowed to breastfeed her. I cried for many months, I couldn't talk to her until she was nine months old. God is punishing me ... life is now a great sadness. They just took my baby away for eight hours and no one said anything, everyone stayed away from me. I was terribly worried. I wasn't allowed to breastfeed. Finally, I made them tell me."[14]

These are a few examples of the typical negative way in which parents were informed about their child's condition. This negative experience was often heightened by hospital staff who were seen as avoiding them. Parents reported:

"They didn't know how to talk to me"; "They couldn't handle it"; "They told me to put her into a home".

Not being informed is often worse. Parents are left with overwhelming feelings of guilt and inadequacy."

"They (the doctors and psychologist) kept saying there was nothing wrong and they blamed it on us. They called it 'environmental retardation.' When he was four-and-a-half years, they finally diagnosed him as functioning at a two-year level and being overactive. It was a great relief that it wasn't me."

"Now he's been diagnosed as retarded, we can do something positive. My wife used to cry all the time and ring me at work everyday because she couldn't cope with the situation. I couldn't concentrate on my work through worry."

Parents often feel that there is no esteem for their child, they and the child are treated as objects, and not as valued members of society:

"The doctors are not interested in your feelings. The doctors see her as different, a specimen. They have no respect for her as an individual. There are always 15 students poking at her, everyone saying how strange she is. They did hundreds of tests on her, but no one ever told us what they were for or what is really wrong with her."[15]

The birth of a disabled child may signify the end of a "normal, taken-for-granted reality" for the parents. What happens from then on may have significant repercussions, not only for

the primary socialisation processes concerning the child, but also for the self-image of the parents and the family. It is not only the child, but also the whole family that comes to "stand out".

The early experiences, with their strong emotional overtones, necessarily influence the primary socialisation process that children with impairments experience. Notions of reality, a sense of self and identity are reflected through parental experiences from the beginnings of life. The self images constructed in early childhood are carried along throughout life and are important determinants in the transition to adulthood. Little research has gone into this socio/psychological aspect of the development of children with impairments and, consequently, not much is known of the types of gaps in the socialisation process that results in handicapping individuals in their transition to adult life.

Winnicott, the well-known British child psychologist, argues for the positive nature of "immaturity" during the period of adolescence. It is during this period that irrational and deviant behaviour can be given expression. He claims that such uncontrollable and risky behaviour is a very necessary precursor to creativity and building up of new social images. Therefore, even though adults may feel threatened, and are tempted to set up strict controls, they need to accept to be confronted by adolescents, in order to leave room for renewal in society and in relationships.

Because life tends to be organised around the disablement, the room for "immaturity" seems even more threatening to the environment for disabled adolescents. Even greater conformity to social norms is required to avoid any "harmful" or risky situation. The "eternal childhood" myth may then be another protection against having to deal with difficult and conflicting realities. The price paid for the "security" is excluding disabled young adults from participating in creative solutions to today's social problems.

The British Council of Organisations of Disabled People, together with Dr. Mary John, writes:

> "The eternal children myth has legitimised the creation and maintenance of sheltered employment, segregated special schools and residential institutions staffed by able-bodied people for disabled people. By keeping fellow citizens apart these institutions, in particular, have had a devastating effect on the lives of disabled people. The isolation has drastically reduced the opportunity for disabled people to develop our interpretation of the kind of world that we would like to live in. It has prevented us from participating in social pressure and campaigning to achieve such a world and, in turn, it has prevented us from learning, gaining confidence and maturity from taking part in such social experiences. It results in ignorance amongst our peers, and the experts, because it prevents mutual learning through shared experiences."

Later on they state:

> "The special education system, then, is one of the main channels for disseminating the predominant able-bodied mind perception of the world and ensuring that disabled school leavers are socially isolated. This isolation results in passive acceptance of social discrimination, lack of skills in facing the tasks of adulthood and ignorance about the main social issues of our times. All this reinforces the 'eternal children' myth and ensures that at the same time disabled school leavers lack the skills for overcoming the myth."[16]

The role of the mentally retarded person is seen as that of a dependent, helpless child. Let us listen to what mentally retarded persons have to say about this:

S: "It's not good for us to be overprotected. Our parents really should allow us some freedom; to go shopping, go to the post office and things like that. I am allowed to do that, and I am thankful to my mother for letting me. Recently she even let me wash my own stockings. I think it is just normal that I should do a thing like that, just as shaving and all that. You can't always be treated like a small child."

LG: "Well, if you never learn to do things like that, what would happen when your mother and father die? How could you manage then?"

S: "That's why I am thinking of an apartment of my own – to be able to live my own life when my parents are gone, not having to be dependent on others. My parents won't stop me. I can move when I like to."

SB: "I know many who are living with their parents and are not allowed to do anything, not even to travel by themselves in the underground. That is really stupid, I think. My parents want me to be independent. I can come and go just as I like. But several of my friends are not allowed to do that. Usually parents are overprotecting us; they don't think we can do anything on our own."

M: "It is just the same at the boarding homes. The personnel behave almost like parents. Even if you know you can deal with money, they won't let you. Maybe there is someone at the boarding home who can't. They buy records and other unnecessary things. Then they will not allow anybody to have money of their own. The others will get envious, they say."

LG: "But that is none of their damned business. Those damned idiots! If they don't allow you to have money of your own, how are you ever going to learn to be independent? It's just tragic! I know a lot of persons who are living in boarding homes and can't handle money. They never had a chance to learn. And it's the same thing for those living with their parents until they die. They end up in institutions because they never learned how to deal with money, go to a bank or a post office. Why can't everyone be given a chance to learn?"

O: "Where I live everyone is interfering when you want to buy something. But I just ignore them. I buy the things I want to have with my own money. The money I have earned is mine; I won't let them take it. But, of course, there is the clothing money. To use it, they have to go with you. So they are always with me when I buy clothes. Once I wanted a particular pair of winter shoes. They were really nice, with sheep wool in them. But they wouldn't let me buy them. They were too expensive, they told me. So we went to a shop with cheaper shoes. But that was stupid. The shoes we bought were almost as expensive as those I wanted in the first place, but of much worse quality. But that's what happens when you have to obey others. I am the one who'll wear those clothes, not them. I don't interfere with what they buy. But they constantly tell me what to buy. That way you will never learn to visit shops, make choices and buy what you think is best for you."

S: "Sometimes we need help. Then I think it is right that they help us, but otherwise we should manage on our own. Or sometimes one of your friends can help you, if he knows how. If you don't want help, you shouldn't be helped. And when I really need help, I have to let them know. If I don't ask for help, I want to do it on my own."

O: "But they think you are just stupid; that you can't do anything by yourself. It's just like when you have to take a bath. Several times I told them I can take a bath on my own. But oh no! I have to wait until they get there to help me. You can take a

shower on your own. But not a bath. You have to take a bath every week and then they have to be there to cut your nails and things like that. It is all wrong. You'll never learn that way. If you move to your own flat, they can't expect you to look up some woman and ask her to help you cut your nails. You have to learn to do it yourself."

M: "It's just the same at the boarding home where I live. They always want to help you bathe, cut your nails and all that. Even if you want to do it yourself, they won't let you. They will just stand there, controlling whether you are washing yourself well enough. When it's male personnel, it is really embarrassing. If you try to do it quickly, they will just say, you are not doing it properly."

LG: "What the hell, this is a lousy way to behave! There is something called personal integrity. If we want to take a bath on our own, we should be free to do so. We have to do something about all this stupidity! You are capable of washing yourself; why the hell should they be there staring at you? And you, oh! you should just push them out of the bathroom. Out with them!"

O: "That's it. From now on I will tell them that I want to be alone when I am taking a bath. No women allowed! I'll just carry them out. I can do it myself – bathing, cutting nails, cleaning ears. But maybe I need help to do the weighing. I don't know how to do that. It is just as though the superintendent wants me to be surrounded by a lot of maidens. She tells me: 'You can't manage on your own, what will happen to you? You will never be able to leave this place. You are not capable of living on your own. You need a lot of child nurses.' But she can't really know whether I can live on my own. But that's what she says when she gets angry."

LG: "So you have never tried living on your own?"

O: "No, I never had that chance. They shouldn't say things like that when they don't know. It was just the same with my job. I couldn't do it, they told me. But now they can see for themselves. I can. I am sure, if I could move to a flat, that would work too."[17]

Institutions with their internal norms and social mores are as powerful, if not more, in teaching their clients who they are, how to behave and how they must view themselves.

The increasing awareness of the secondary consequences of labelling has led to its criticism in recent years. With the move toward integration policies, some advocates propose the elimination of labels altogether and suggest alternate strategies of identification of needs. This is an important policy issue and will be discussed further. Despite the polemics, however, the issue of getting services, resources and professional help to those needing them remains an essential one.

III. BECOMING AN ADULT

1. Stages of Development

Ideally then, adolescence is a period when new roles are taken on, one's self-image, after some turmoil and conflict, is consolidated, independence and autonomy from one's parents are gained (after considerable battle in many cases) and one is ready, with the support of one's peers, to envisage entry into adult life. The following are some of the important social and psychological elements involved in trying to become an adult:

Socialisation and Peer Groups

Belonging to a group, sharing its norms and values and feeling accepted by its members is an important step for young people in coming to accept themselves. Many studies of the "youth culture" show how the peer group functions as an important terrain where young people can test their new roles, work out conflicts and co-operation as well as identify with others who share their problems, values and position in terms of the adult world.

Are disabled young people a part of the youth culture? What opportunities do they have to function in groups together with non-disabled and disabled peers? Sociologists working on the socialisation of youth talk about the importance of the integrative function in identity formation, that is, the importance of social participation and belonging to a group to enable the internalisation of social values and norms. The establishment of the assertive function is equally important in the development of individuality and autonomy. It is through interacting with others that people learn to defend their individual views, assert their independence and situate their own feelings and relationships to others.

> "Of course, many handicapped young people have little or no experience of the real facts of the social life led by the non-handicapped because they have so little contact with able-bodied peers. For many, this may be protection against feelings of extreme loneliness, but in some respect, for example in relation to anxieties about feeling unattractive to members of the opposite sex, the young people's ignorance of the fact that many of their fears are similar to those of non-handicapped teenagers serves only to enhance their feelings of isolation and difference."[18]

Feeling that one belongs to a group and shares equal status with others is an important exercise in considering oneself as being part of adult society and holding a role in it. It is also essential to the process of making social rules one's own, and being capable of role-taking in relationships with other people. It means being able to take on other persons' perspectives and sharing their meaning of reality. This is based on feelings of being equal to others, having the same rights and responsibilities and thus being able to have a share of the necessary power to carry out action. A pertinent illustration of this is given by Finn Carling[19]:

"A contact on equal grounds, that is the goal of our endeavours. ... I will tell you about one of the happiest moments of my life, a story about a meeting on equal grounds. It happened in my first term at university that I was going into the small library of the Institute of Psychology. I did my utmost to be as silent as possible, but I did not think of the rather high threshold, so I suddenly stumbled, shot like a cannonball into the room and hit the table with a bang. There was, unfortunately, a bottle of red ink on the table and, yes, it did happen. When I rose, my face was as red as a communist's heart, and the bottle lay empty on the floor.

For about a second, my fellow students were dead silent, then they all burst out laughing. They roared! They did not try to strangle their merriment for fear of hurting me. They knew that they couldn't as I was one of them, a fellow student, a friend. Why shouldn't they then laugh at me?"

The social development of a disabled child is likely to differ in significant ways from that of his able-bodied peers. The disabled child tends to lead a double life, that is, having role-taking experiences typical of other children his age within the family circle and possibly with some friends while being simultaneously exposed to alienating social pressures of handicap outside this protected circle. Therefore, the disabled child will undergo one form of social learning based on the evidence of equals and the assumption of a just world and another form of social learning in which he constantly encounters the injustice of the world. This split necessarily affects the person's social development.

"The root of the matter is this: each stage of social development presupposes a certain balance of power between the child and the social world. Further, it opposes to this balance of power a clear-cut set of expectations of what ensues if the rules governing social behaviour (as the child perceives them) are obeyed. For a handicapped child, both sides of this equation are altered by the devastating social meaning of his handicap. On the one hand, at every age he possesses less social power outside the family than his able-bodied peers. On the other hand, he is constantly exposed to incompatible kinds of moral role-taking experiences. Both within the charmed circle of the family and in the outside world, the handicapped child is constantly defined in two socially contradictory ways: as a complex, growing child who, among other things, happens to have a handicap and as handicapped, a freak, a perpetual patient, an object of pity, contempt or despair.

In the lives of some children, the lines of this division in social experience roughly parallel the division between the family and the outside world: they are usually treated as persons in the home and almost always defined as handicapped elsewhere. For other children, the sociological chasm cuts across all boundaries: both at home and in the outside world they encounter in full measure both kinds of experiences."[20]

Separation from Parents

The issue of separation from parents at the end of adolescence and the beginning of adulthood is a complex interaction of psychological, social and economic aspects. There is no ambition here to doing justice to this difficult question; only a few key points will be raised.

For all young people, independence and finding one's personal autonomy is intimately linked to separation from parents. The prolongation of adolescence, and the weight of youth unemployment are presently factors that add to this already-difficult transition. Self-confidence in one's capacity to "make it" on one's own, without the support of parents is an

essential motor to separation. Parents' confidence that young persons are able to stand on their own feet is an additional impetus to this fragile process.

For young people with disabilities, this moment is complicated by the "subjective" factors discussed above that make self-confidence such a difficult victory. These are added to the practical material and technical difficulties.

The problem of separation is linked to the attitudes parents have developed to their child's disability, and the type of family relationships that have resulted. As mentioned beforehand these attitudes are highly influenced by how the disability was announced at birth, and the position that the professional environment took at this crucial moment. Research has shown that parental attitudes are highly influenced by their surroundings and what they think others will think of their disabled child.

Parental attitudes are seen to range from acceptance, perfectionism, over-protection and disguised and open rejection. However, stereotyping parents of disabled youngsters is just as hazardous as labelling, for it implies that change and learning are not possible. The role of parent organisations and counselling have had an important effect in helping parents accept developmental changes in their children, and therefore accepting adult independence.

Institutions as Barriers to Autonomy

One of the toughest barriers to becoming an adult for disabled young people has been the "total institution". Although the tendency today is toward integration, therefore "deinstitutionalisation" in most countries, the mark left on social attitudes and practices has been almost indelible. The links between institutionalisation and labelling have already been mentioned. Total institutions, by their very nature, tend to deprive inmates from achieving an adult role – first of all, by the social and physical barriers they provide against the outside world.

Privacy is not possible in institutions. The diversified aspects of adult life on the other hand – the division of boundaries between the home and the work place, for example, allows for a private, personal self to develop. In total institutions work, play, relationships with others, sleeping, eating, etc., all happen within the same walls, under the surveillance of the same staff. The only other time in an individual's life that this kind of "totality" occurs is in infancy before school age, when the child is kept in the home and is dependent for everything on his parents. Nothing escapes the look of the mother; the child has no privacy.

Gwyneth Ferguson Matthews tells about the lack of privacy in a rehabilitation institution:

> "Shannon had been at Birchwood six years, and her deep unhappiness was palpable. ... They complained about the lack of privacy which went far beyond the no-screen situation I had spotted. According to them, no one ever knocked or closed doors. Shannon: 'The first thing I see every morning is a naked male quad. He's across the hall from me, and when they bathe him, they don't close his door. I'm no prude, but I don't like looking at a naked quad; it's an invasion of his privacy, and of mine'."[21]

The child status in institutions is also underlined by the lack of significant work to be done. The working role, if there is one, is a kind of "make believe" that everyone knows doesn't count. Usually there is no payment, or only a token retribution.

> "Sometimes so little work is required that inmates, often untrained in leisurely pursuits, suffer extremes of boredom. Work that is required may be carried on at a very slow pace and may be geared into a system of minor, often ceremonial payments, such as weekly tobacco ration and the Christmas presents that lead some mental patients to stay on their jobs."[22]

The role of worker is replaced by the "feeling like a slave" within institutions:

"Many times I think I have been like a slave. It shouldn't be like that. You have a right to live a life of your own, so that you can become like others. To be able to make your own decisions, so that you don't become like a horse or a cow. Now I think it's difficult to believe that I could take it for thirty years."[23]

Because people with disabilities are seen to be incompetent in meeting their own needs, the institution is there to satisfy all their requirements. This is the basic underlying premise that justifies robbing inmates of all autonomy, responsibility and any attempts at independence. The overprotection goes so far that persons are not given the occasion to make mistakes, take chances and "get hurt" – all the essential steps in becoming an adult.

Sexual Relationships and Marriage

Besides obtaining employment, the other major mark of adult status in today's industrial societies is marriage, living with a partner and having children. Although this is a given fact of life for most young people, those with disabilities must trespass attitudinal and material barriers to have access to this taken-for-granted adult role.

As already mentioned, social isolation is a problem for many disabled young people.

The Elizabeth Anderson study found that pupils attending special schools never saw their friends outside school, that after college, friendships were lost and that disabled young people had difficulties developing and maintaining friendships, which are so important for social maturity. It is suggested that friendship may be the only emotional contact for some disabled young people.

Because it is likely that many teenagers will not have the opportunity to marry or have children, it is most important to spend some time discussing this, emphasizing the value of close and fulfilling friendships and companionship outside marriage. Schools should ensure that someone from outside is available to talk to teenagers both about general problems related to handicaps and in particular about sex and marriage.

The subject of sexuality for disabled young people seems to be even more of a taboo subject than for those who are not disabled. Often the question is treated as a medical or moral issue of reproduction and rarely as one of desire, emotional need and as part of adult life.

Because of the pressure in our culture to deny the sexual identity of the handicapped, it is especially important that those who work with handicapped children and adults possess a sensitive and enlightened view of sexuality. This is actually beginning to happen in the field of adult rehabilitation. Traditional taboos on sexual activity between adults in hospitals and other institutional settings still prevail, but sophisticated sexual counselling of newly disabled adults is much more common than it used to be.

Increasingly, examples of married life of disabled people are being communicated to the public through the media which is gradually breaking down some traditional prejudices. What are the gaps in services and support systems that could facilitate married life for disabled adults? The right to have and raise children is another question that cannot be avoided.

Finn Carling's own words concerning his youthful anxieties about marriage are a good illustration of how social attitudes may contaminate personal desires and may act as an interdiction for young people:

"It was not only the thought of how to make a living, however, that occupied my mind in my youth. I also thought of another important side of the life of the adult: marriage. Whether it was the apparent stability of the institution of marriage that tempted me, I could not say; I just know that I thought more of marriage than of love, at least during

some periods, and that I was extremely excited when I heard about marriages between crippled and normal people, although I tried to conceal my excitement.

What I heard, however, did not at all encourage me, as it usually reflected the ideas people had about these marrriages. I heard about the 'nice and handsome' gentleman who had just married 'that lame girl' and 'what on earth do you think made a pretty girl like her throw her life away by marrying that man in the wheelchair?' 'Well', the reply would be, 'she has always been the sacrificing kind, you know!' It did not occur to them that marrying a cripple could be anything but a sacrifice. That those who marry the disabled consequently get the worst of it is a feeling so deeply rooted in the minds of people, that they nearly always find it a little queer when a healthy young man or woman marries a cripple. Not that they directly disapprove of it, i.e. if it happens outside the family; they just do not realise that it can be like a 'real' marriage. I have a feeling that it is just because of mere luck that I have not heard the following variation upon a rather well-known theme: Do you want your daughter to marry a cripple? Even the teenagers themselves showed this attitude, and the girl who wanted to be with a crippled boy did not only have to stand up against the pressure of her parents, but also that of the group."[24]

Marriage and a family are not only outer signs of "adult status", but serve as hallmarks of "normality", of being like others, doing what others take for granted as their right as human beings. For young people with disabilities, these "rights" are often considered as being extraordinary when achieved and serve as a tremendous boost to the self image:

"Today, we are going to buy the engagement ring, and I feel very excited. I never thought that these things would happen to me. I feel so elated and more human than I have ever done. Maybe this is what I have been waiting for – to be accepted by Kathleen has removed many of my insecurities. To realise that I am capable of such strong emotions and to realise that they are reciprocated is tremendous. I am just like any other man. I am going to be married."[25]

2. The Significance of Work

Despite the spreading rumour that the traditional "work ethic" of western societies is rapidly declining, the significance of work as the major proof of adult status and active participation in society remains uncontested. The work one does not only defines one's place in society, it determines largely the material quality of life, but also impinges upon one's sense of competence and self-esteem. The extent of unemployment, especially youth unemployment, is making these truisms even more pertinent.

In 1977, at the beginning of the youth unemployment crisis, OECD held a high-level conference on this issue. The Honorable Ray Marshall in his opening statement underlined the significance of work for young people:

"Unemployment in any form is destructive to the individual who is out of work and to the society in which that individual lives. All of us represent countries that are facing the challenge of maintaining economic growth. We cannot afford to lose the productivity and the contributions of people who are able to work and who want to work ... not having a job for a protracted period can erode their self-confidence and sense of individual worth. This experience can give rise to psychological problems, marital difficulties and even suicides. The despair and hopelessness produced by youth unemployment can damage the social fabric."[26]

These words are indeed a strong plea about the significance of work for young people, both from the psychological and social point of view, as well as being a clear indication of the strength of the value of work in general. The research carried out by the Steering Group for Youth Unemployment since the conference showed that not all youth share the plight of unemployment despite general economic difficulties, but that there is a minority group that is particularly hard hit. "Membership of this 'hardcore' group is not randomly distributed over the youth population. Instead youth with multiple socio-economic disadvantages, e.g. lack of education, physical and/or mental handicaps or early pregnancies, are most likely to comprise the bulk of young people in this category." In terms of economic policy, "The distribution of youth unemployment – falling heavily on educationally, socially and economically disadvantaged young people is such that unless effective measures are taken to tackle their unemployment problems, some unemployed youth are in danger of becoming permanently dependent on social welfare assistance. Intensive policy interventions in favour of those young people with serious labour market problems are therefore an important public investment for the future on both equity and efficiency grounds."

Acquiring a job fulfills a number of psychological functions. The first of these is the sense of personal identity which a job gives, including self-esteem, responsibility, dignity and acceptance as an adult member of society. More often than not, people are categorised and valued, at least on first acquaintance, in terms of what they "do". The problem of how to answer the question: "What do you do?", and the reaction of the enquirer is, for a disabled young adult who does not fall into the category "student" or "housewife", a constant reminder of being "different", confirming and increasing the lack of self-confidence and devaluation of self which may be already present. There is now an increasing literature dealing with the effects of unemployment on the self-image of able-bodied school leavers and of adults, and there is no reason to suppose that its effects on handicapped school leavers will be different, since the orientation of special education is generally also towards employability, wherever possible.

The question of the development and preservation of a sense of identity is particularly acute for severely disabled young adults. The metaphor of being "imprisoned" is often used to describe those whose disabilities make voluntary movement, or any but the most rudimentary and laborious forms of communication, impossible. There seems to be a parallel here with Cohen and Taylor's research[27] into the "inner subjective lives" which long-term prisoners develop. In working with these prisoners, the authors gradually realised that getting through each day, let alone each month of the year or decade of the century, was much more problematic a journey than they had ever taken it to be. The central question was about how to adapt to prison life. In what ways should one resist or yield to its demands in order to make life bearable, in order to preserve some sense of identity ... behind this question lay their greatest anxiety ... the sense of imminent deterioration ... consciousness had to be monitored ... against the insidious processes which attacked personal identity". Society tries to reassure and excuse itself by reiterating that it must be different if one is born with a disability – and congenitally disabled people often compare themselves favourably with those acquiring handicaps later in life. Nevertheless, the fear of intellectual deterioration and loss of personal identity because of the lack of a meaningful job is a real one among many disabled people and their families.

A second important psychological function of work is that it enables an individual to feel that he or she is making an active contribution to the community. In some cases, particularly in the service industries, the work itself or its end-products can be seen as useful, although of course in many jobs this aspect of work has been lost and the only way in which an individual can feel he is contributing to society is by being self-supporting. A survey carried out in the

United Kingdom has also shown that it is a major motivation in the wish of many retired people to continue working, at least on a part-time basis (e.g. the Employment Fellowship, an organisation set up to help retired people to find work, reported that 30 per cent of retired people would like paid work[28], in most cases on a part-time basis).

A third function of work is the opportunity it may give for widening one's social contacts. Not only does work provide a change of environment – which is desirable for everybody, but which may be of particular importance to those living in institutions – it also provides, in many instances, a new range of social contacts and for handicapped young people, perhaps their first real opportunities for mixing with and making friends with their non-handicapped peers. It can thus assist their social development and add to sheer enjoyment of an interest in life of those whose leisure time is restricted by poor mobility and lack of friends. The need of handicapped young people to find companionship through work, or an equivalent "alternative" is of course shared by other groups in the community. It is one of the main reasons given by retired people, especially women, for wanting part-time work. It helps to explain why large numbers of women with young children now either go out to work or, if they do not, wish to do so. An important study carried out by Brown and Harris[29] on the social origins of depression showed that one of the main factors making a woman vulnerable to becoming clinically depressed in the face of either a severe stress or an "ongoing major difficulty" (and all severely disabled people have such difficulties) was whether or not she had a full or part-time job. If she did, this had a protective function and she was much less liable to become depressed. One way in which the authors explain the mechanisms at work is that having a job provided her with a sense of self-esteem and also increased her chances of making new social contacts and developing new interests.

A fourth psychological function of work is that it does, even when it is boring and repetitive, provide a structure and a regular routine for the day. Most people, whether or not they are disabled, need this framework; and young people who have attended special schools and institutions where the day is often highly structured for them and where little thought has been given to teaching them how to structure their own lives are particularly liable to do so. Cohen and Taylor, in *Escape Attempts*, begin thus:

> "This is a book about everyday life, the precariousness of that life and the tenuousness of the identities that we create with it ... rarely in the elegant theories, the careful research (of sociologists), does everyday life appear. There are few accounts of boredom, elation, despair, happiness or disappointment, no sense of the one obsessive problem which we always knew was ours ... how to get through the day."[30]

For the disabled, whose hopes of leading a life similar to that of their non-handicapped peers have suddenly been dashed, this problem of how to get through the day must be enormous; it is already evident in the boredom and loneliness reported by numerous disabled adolescents during their school holidays.

Finally, another important role of work should not be forgotten and that is that it is an institution where secondary socialisation takes place, just as in educational institutions. Secondary socialisation is an essential part of becoming an adult, of learning social skills and situation-specific roles, such as how to be a worker, a colleague, someone who gives instructions, someone who follows instructions. This essential process allows the individual to try out behaviours and develop distance from the immediate family setting. For young people with disabilities, coming out of overprotective families, where they were maintained in infantile roles, or total institutions, where they only knew how to be passive and obedient, this may be an essential step toward adult life.

Alan Counsell's experience in his first job illustrates this point:

"On reflection, all the weavers have contributed much to my social training. Having formed few relationships during my early life, I did not understand or know how to handle the acceptance that the weavers showed to me. I would take advantage of these relationships and pull the weavers' hair or untie their aprons and be very childish and cheeky. The weavers would clip my ear, and I soon learned how to behave better with people. I doubt if any of them were aware of what they were teaching me."[31]

3. Adult Status Before the Law

Legal adult status implies being recognised as an adult citizen before the law, with rights, privileges and responsibilities. In principle, all citizens are equal before the law, however the law then makes a distinction between those who may be considered as adult citizens capable of enjoying rights and carrying out responsibilities.

Joseph Goldstein, in an article on Being an Adult in Secular Law[32], states that the first and foremost criterion for adult status is chronological age, and the rite of passage in secular law from childhood to adulthood is simple, certain and easy to establish – at the magic statutory age of majority one is considered to be "independent" of parental control and protection and is presumed to be competent to take care of oneself – to make and to be responsible for one's own acts and decisions.

Adults are presumed to have the capacity to make binding contracts, to hold and to dispose of property, to marry, to vote, to hold public office, to consent to or reject medical care, to commit crime, to take testamentary dispositions, that is to engage in any activity and to be responsible for it. However, in the making and the administration of law, there is a constant tension between serving the interests of the state and safeguarding the autonomy of each person to pursue his interests as he sees them – that is, to give his own meaning to being adult without coming into conflict with the law.

Some people, however, are disqualified from adult status and this is where the questions of labelling, as discussed beforehand, interface with legal adult status. Criteria for disqualification rest upon "scientific" expertise that justifies declaring an adult no longer competent to give his own expression to being adult.

"He is classified incompetent to care for himself, to manage property, to contract to marry, to divorce, to be a parent, to stand trial, to serve on a jury, to vote, to hold public office, to commit crime, to be executed, or to make a valid will.

The population of adults, or the ambit of choice for some of them, is thereby reduced under statutes which entitle the state, as parens patriae, to adjudge age-qualified persons 'incompetent by reason of mental illness, sickness, drunkenness, excessive use of drugs, insanity or other mental or physical condition'."[33]

Goldstein goes on to state:

"The harmless incompetent may be placed, like a child, in the custody, care and control of an adult guardian. Moreover, those 'adults' whom the state declares in accord with the established science to be either 'dangerous to self' (undefined) or 'dangerous to others' (undefined) may be incarcerated indefinitely to prevent self-injury or violence to others. These processes for disqualification, including provisions for restoring an adult's 'competence', are inherently offensive to individual autonomy."[34]

As with performing the adult roles discussed beforehand, the question of "legal adult status" is not something that young people with disabilities may take for granted.

The basic paradox concerning legal adult status can again be related to the question of how disability is defined. Legal adult status assumes certain competences and capacities to carry out adult roles. Because disablement is viewed as making one "incompetent", full adult status is not thought possible. It has been argued throughout the text that the operational definitions of "incompetence" are both arbitrary and dependent on non-rational attitudes and prejudices. It is as a result of such attitudes and prejudices that disabled persons may be disqualified from adult civil rights and being recognised as adult by the law. This fact underlines the importance of "subject" oriented strategies for defining and evaluating incapacities of disabled persons, as pointed out above in the discussion of alternatives to labelling.

For persons considered to be mentally disabled, the issue of legal adult status is even more complex. For others, the right to employment, normal housing, owning property, etc. may be endangered. For persons with mental disabilities, the risk of disqualification from adult status may extend to marriage, having children, education, living outside an institution, etc.

In a report on the Civil Rights of the Mentally Retarded, Bellamy, Beermann, DiRocco, etc. wrote:

> "The practice of attaching labels to people has generated considerable controversy in the last two decades. Numerous persons and groups are disturbed about the wide ranging effects of labels and their concern is increasingly being translated into active protest. Racial and ethnic groups, women, the old, the young, the mentally ill and the mentally retarded are among those engaged in protest against perceived injustices resulting from the inappropriate or unnecessary labels. Such protests have moved from moral and philosophical pleas for fair treatment to the demand for remedies through legislative and judicial channels."[35]

Being labelled mentally retarded in the United States at the time of the report (1973) allowed adult access to vocational rehabilitation services, but could also prohibit one from securing certain occupations. A person could be excused from responsibility in a criminal suit, and the same label could prevent them from serving as a juror appearing on his own behalf in a civil suit, or serving as a witness. A person could have his or her marriage declared as null and void because of mental deficiency; a happily-married couple could have their children taken away and placed in foster homes if either parent was judged to be retarded. Mentally-retarded persons could be sterilised in some states without their consent.

The report goes on to point out:

> "The familial and personal rights of persons labelled retarded have received less popular attention than the rights to education and habilitation. This is unfortunate since the label 'mental retardation' can affect many personal rights and privileges which are normally taken for granted. Among the relevant issues are civil liberties, the right to marriage, termination of parenthood, sterilisation and guardianship."

Today, the rights of disabled persons to legal adult status is in the forefront of discussion at the different levels of policy making, in institutional practice and among disabled persons themselves. The civil rights movement in the mid-60s and early 70s in a number of Member countries paved the way for new attitudes toward equal rights for disabled people. The World Programme of Action Concerning Disabled Persons that was formulated by the United Nations outlines the concrete goals to be reached within the Decade of Disabled Persons, 1983-1992. Under the chapter promoting the equalisation of opportunities and concerning the role of legislation, it is stated:

- Member states should assume responsibility for ensuring that disabled persons are granted equal opportunities with other citizens;
- Member states should undertake the necessary measures to eliminate any discriminatory practices with respect to disability;
- In drafting national human rights legislation and with respect to national committees or similar co-ordinating national bodies dealing with the problems of disability, particular attention should be given to conditions which may adversely affect the ability of disabled persons to exercise the rights and freedoms guaranteed to their fellow citizens;
- Member states should give attention to specific rights, such as the rights to education, work, social security and protection from inhuman and degrading treatment, and should examine these rights from the perspective of disabled persons.

It is this last statement "from the perspective of disabled persons" that implies fundamental changes from past administrative and policy measures. In another part of the charter, explicit recommendations are made to the participation of disabled persons in decision making:

- Member states should increase their assistance to organisations of disabled persons and help them organise and co-ordinate the representation of the interests and concerns of disabled persons;
- Member states should actively seek out and encourage in every possible way the development of organisations composed of, or representing, disabled persons. Such organisations, in whose membership and governing bodies disabled persons, or in some cases relatives, have a decisive influence, exist in many countries. Many of them have not the means to assert themselves and fight for their rights;
- Member states should establish direct contacts with such organisations and provide channels for them to influence government policies and decisions in all areas that concern them. Member states should give the necessary financial support to organisations of disabled persons for this purpose;
- Organisations and other bodies at all levels should ensure that disabled persons can participate in their activities to the fullest extent possible.

These recommendations, as well as the supporting statement of this approach, made the ministers at the OECD Conference on Active Life for Handicapped Youth underline the view held in this report that future policies in this field are tending toward a more "subject" orientation. "Subject" orientation means that persons are subjects and not objects of measures and that their own views are taken into consideration. In other words, disabled persons are considered as adults and not eternal children for whom decisions must be made.

IV. TOWARDS A SUBJECT-ORIENTED APPROACH

1. Handling the Dilemmas of Labelling

Increased awareness of the negative consequences of labelling for the self-esteem and identity of disabled persons has caused administrators and policy makers a practical dilemma: how best to meet special needs without increasing disablement and how to identify those requiring support without placing them under the burden of negative labels. These questions have significant implications for the issue of adult status for disabled youth. The present section tries to link adult status to labelling and make some practical suggestions as to alternative approaches to administrative problems.

The basic dilemma behind classifying people into categories is that the manifest aim to make it administratively possible to provide them with services to meet their needs very often has the latent consequence of handicapping them by the very same instrument. Labels place people in special categories, outside the system, thereby pointing out what makes them different and thereby making them vulnerable to rejection by society. Labels may open the world of assistance, but close the world of adult participation.

The World Health Organisation (WHO), with the help of Dr. Phillip Wood, tried to improve the necessary evil of categories by developing a distinction between impairment, disability and handicap and drawing up an international classification system. The project had originated from reflection on the influence of social processes on the response to chronic illness and the extent to which epistemology and language determine perception and appreciation of problems. It was also intended to alleviate some of the negative effects of the medical model, that is, situating handicap as being internal to the person, i.e. as a disease or pathology. "Impairment" is defined as "abnormality in psychological, physiological or anatomical structure and function", and is to be distinguished from a "disability", that is, any restriction or lack of ability to perform an activity in the manner or within the range considered normal for a human being. A "handicap" is a disadvantage for a given individual in a given situation that limits or prevents the fulfillment of a role that is normal for that individual. Disabilities are therefore linked to basic activities such as walking, seeing, holding, talking, etc., whereas handicaps, although they may typically arise from such disability, are the result of the opportunity of fulfilling basic roles within a specific situation, such as the working role, independence, social integration, adult role, etc. Therefore, disability and handicap are not in a direct causal relation, just as an impairment does not necessarily result in either a disability or handicap. Handicap, then, is socially determined and can therefore be alleviated, diminished or eliminated through policy measures.

An expert workshop was held in Sweden in 1984 with Dr. Phillip Wood to discuss the WHO classification system and its consequences. A number of interesting questions were raised and suggestions made by researchers and specialists in the field. Professor Nordenfelt of Sweden questioned the causal relationships implied by the classification system under the grounds that such causality, i.e. impairment-disability-handicap, are still close to the medical

conception of disease-disability-handicap. But above all, he criticised the fact that WHO's classification system conserves the notion of impairment as *abnormality* in function and disability as not being able to perform an activity in the manner considered *normal* for a human being; and handicap as limiting the fulfillment of a role that is *normal* for the subject. He pointed out the situational and cultural relativity of "normality", and suggested the notion of the capacity to carry out *vital goals* within the context of *standard* rather than normal situations, given that a standard situation in Sweden is very different from a standard situation in Africa. Such more neutral and relative terms within the classification system are intended to eliminate the normative attitudes linked to the "normal/abnormal" dichotomy.

Another participant, Swedish researcher Marten Söder, elaborated further on the notion of "normal environment" and spoke of the Swedish definition as being the following: "handicap arises in the confrontation between an individual with an impairment or a disease and an imperfection in the environment or in an organised activity that makes accessibility difficult or impossible for him". The WHO definition takes the environment for granted, even though "handicap" is no longer considered as being "within" the individual but as the result of interaction between the individual and the environment. As long as the environment consists of social roles that are "normal", the inability to live up to the requirements of these roles puts the individual in a disadvantaged position and thus creates a handicap. In this way, the rehabilitative, medical approach is conserved since changes must be brought to bear upon the individual rather than the environment. Within the Swedish perspective (also found in many other countries), it is the environment that is to be changed and that is the object of social policy interventions.

This classification system and its reconstructions (i.e. what Söder calls the Swedish definition) have direct consequences for policy decisions.

Wood's task for WHO was to come up with a less handicapping classification system for identifying people requiring special services and financing. However, by perpetrating the medical logistics, as stated above, the system cannot fully reach this goal. The revised version, however, makes it possible to ask questions about the complex relationships between the individual and the environment and how values and attitudes influence this relationship, what social processes help or impede the transformation of disabilities into handicaps, what kind of message is communicated to the disabled person by professionals and how this influences his self-image and his chances of not being handicapped.

Another aspect of definitions was discussed: that of who does the defining and the consequences this has both for social policy and for disabled people. Dr. Mary Croxen, UK researcher, spoke from the perspective of Disabled Peoples' International and pointed out the major flaw in the use of the WHO classification as not having included those directly concerned in the identification and definition of their needs. Definitions and knowledge produced by disabled people is very different in its essence from definition and knowledge produced by professionals whose careers and subsistence depend on the service system.

She spoke about the increasing momentum of self-advocacy among disabled people and said that we are now in a period of transition marked by conflict in which disabled people are making clear that it will be they themselves who will define what their fundamental problems are and how much intervention they accept.

2. Alternative Solutions and Self-Definition

The consequences of the various attitudes ranging from the medical to the subjective orientation to disability and how they determine labelling have already been discussed.

Alternative models also stem from this paradigm. One such alternative to labelling is an "ecologically oriented, service-based classification system", as developed by Professor Nicolas Hobbs at Vanderbilt University[36]. Instead of centering on the individual's impairment, this model proposes an assessment of the environmental setting of the individual and tries to come up with practical solutions to the difficulties which arise from the person's interaction with the environment.

The unit of classification, therefore, is not the individual but the individual in a setting. Persons are classified not on the basis of clinical nosologies but on the basis of services required to achieve specified goals at a particular period in their lives. The classical categories of handicapping conditions are not employed and are unnecessary for purposes of service delivery. In order to work out a service plan for a particular person, it may be necessary to have the results of some traditional assessment procedures. However, these are not used to arrive at a diagnosis, but to arrive at a specific service-delivery plan. The expert is not there to propose a constructed set of meanings concerning the disability to which the individual is expected to conform, but to develop a plan of action that will enable the person to live and function within the mainstream. The following is a concrete example:

> François Bergeron, age 19, from a rural area of Quebec, has moved to Montreal with his family and enrolled in a special vocational educational program operated by the Ministry of Labour. Tests show IQ scores in the 60-70 range, reading ability at about the third grade level and arithmetic ability at about the fifth grade level.
>
> François is amiable and hard working, but gets upset and loses his temper when unexpected demands are made upon him. There is some evidence of a hearing problem. He communicates reasonably well in French, but knows no English. He appears to have some musical talent and has taught himself to play the guitar.
>
> All other members of the family, including his mother, have found jobs, and there is no one at home during the day. A company manufacturing automobile parts and employing predominantly French-speaking people had adopted a hire-the-handicapped policy and is willing to help François get a job. François has an older brother with whom he gets along very well. The brother is competent and dependable; he may be the person around whom an enablement plan should be built.
>
> At the planning conference, it is agreed that François needs to be taught, prior to employment, skills in folding boxes of assorted sizes and packing them with small parts in a prescribed fashion. He needs to have a thorough audiometric examination, and the probability is that he will require a hearing aid. He will need to use public transportation to get to work and this will require knowledge of French and English words unfamiliar to him, as well as new skills in getting around. François has not had money of his own before and will need help in managing the money he will receive.
>
> During the job training period, François should be helped to understand that unexpected demands may be made on him when he goes to work, and he should have specific practice in responding to such situations. Control of his temper should be a major responsibility for him. He needs remedial instruction in reading. Additional instruction in arithmetic, an area of strength, may enhance his self-concept as well as improve job opportunities. His talent in music might be encouraged to help in social adjustment. A dental screening examination has shown that François needs to have three teeth filled.
>
> Since François's first job placement will occupy him for only five hours a day and since none of his family is at home, arrangements must be made for him to have something to do in the afternoons. The foreman at the plant where François will work should be

brought in to help guide François's transition from the training program to the job setting. If François does need a hearing aid, it must be fitted, and his parents or his older brother and the job foreman will need instruction in how to teach him to use the device.

It should perhaps be pointed out that while François is mentally retarded, this particular piece of information is of little use. A somewhat similar service plan might be worked out if he were emotionally disturbed or orthopedically handicapped. The focus here is not on the handicapping condition but on the things that must be done to enable François to be employed successfully. The conference record can be recast in terms of a number of specific services to be performed and objectives to be achieved.

Another alternate strategy similar to the ecological approach is the one suggested by Victor Finkelstein, an active member of Disabled Peoples' International and author of "Attitudes and Disabled People"[37]. After a historical analysis of attitudes towards disabled persons during the last hundred years or so, he states that we are now moving into a new phase of history (Phase 3) in which disabled people are taking an increasingly active part in defining their own needs in the face of a disabling environment. He calls for a "materialist" approach to defining disability, wherein the central characteristics of attitudes focus outwardly towards the social and material environment. This focus locates the problem in society and logically leads to a social definition of disability. One such definition has been proposed by the Union of the Physically Impaired Against Segregation:

> "In our view, it is society which disables physically impaired people. Disability is something imposed on top of our impairments by the way we are unnecessarily isolated and excluded from full participation in society. Disabled people are therefore an oppressed group in society. To understand this, it is necessary to grasp the distinction between the physical impairment and the social situation, called 'disability', of people with such impairments. Thus, we define impairment as lacking part of or all of a limb, or having a defective limb, organ or mechanism of the body and disability as the disadvantage of restriction of activity caused by a contemporary social organisation which takes little or no account of people who have physical impairments and thus excludes them from participation in the mainstream of social activities. Physical disability is therefore a particular form of social oppression."

Finkelstein proposes that because a disability is a social relationship, it can be altered. Although seemingly a Utopian view, he goes as far as saying that once social barriers to the reintegration of people with physical impairments are removed, the disability itself is eliminated. Changes to society, material changes to the environment, changes in environmental control systems, changes in social roles and changes in attitudes by people in the community as a whole are called for. The focus is decisively shifted onto the source of the problem – the society in which disability is created.

Michel Oliver, a specialist in social work with disabled people, supports the above self-definition perspective and points out that self-definitions are not only important for the disabled individual but can have important repercussions for the work of professionals. This change in perspective has been known to give rise to conflicts between professionals and clients, especially when definitions of disability and the situation are diverging:

> "Professionals have often been reluctant to accept a disabled person's own definition and have used terms like 'denial' and 'disavowal' to account for contradictions between definitions. The assumption that has usually followed from this is that it is the disabled person who is mistaken or misguided and the professional who is correct. It logically

follows from this perception of a given situation that the social work task is to facilitate a more realistic assessment of the situation by disabled persons themselves."[38]

He goes on to argue that assessment must take into account both individual and social aspects of disability and the relationship between them, and should be undertaken by competent and knowledgeable professionals who understand the wishes, concerns and goals of their clients.

Laurence B. McCullough, in an article entitled "The World Gained and the World Lost: Labelling the Mentally Retarded" suggests some significant improvements on the present practice of labelling the "mentally retarded" and examines some of the ethical issues.

The basic practical dilemma concerning mentally-retarded persons is that in the absence of special treatment, they will probably suffer a loss of opportunity for human development as compared to "normal people". Therefore, labels are necessary to gain a world of special treatment. McCullough's basic ethical question is: must special treatment, the world gained by the label of mental retardation, always be purchased at the price of diminished moral status?

He goes on to say:

"The history of our social and legal response for the retarded has been to strip them of rights and responsibilities across a broad spectrum of educational and job opportunities, housing in the community, voting, marriage, reproduction, etc., simply because they are more than two standard deviations below the mean of intelligence."

The general meaning of "handicap" in sports such as golf or horse racing (imposing a disadvantage on a strong player) becomes an ethical issue when applied to persons who already have a certain disadvantage (impairment) of function, since it imposes additional disadvantages on them by unjustifiably denying them opportunities for the pursuit of human achievement. This brings McCullough to distiguish between the instrinsic and extrinsic value dimensions of handicap, the intrinsic being the diminishment that the handicap *per se* causes. The extrinsic is how others evaluate a label. This evaluation is very relative and depends on public attitudes and values and may vary with time.

"Who would have thought twenty years ago that the mentally retarded, for example, could attend neighbourhood schools or compete in athletic events? Doesn't one have to be of 'normal' intelligence to do these things? How one answers questions about handicaps like mental retardation will, as we now know, have a profound impact on the quality of life enjoyed by the handicapped. That is, how we respond to the behavioural manifestations of mental retardation handicaps as well as 'intrinsic dysfunction'. This is the extrinsic sense of being handicapped."[39]

Another dilemma, especially significant concerning the label of mental retardation, is the notion of a fixed state not open to change or improvement. This may have important policy implications, especially when resources are scarce and when the perspective is one of "rehabilitation". Why put resources into something that cannot be improved?

Therefore, the desired alternative is a "process view", rather than a "fixed state" view, of handicaps and of the human condition in general. The process view (similar to the "self-definition" above or a "subject" orientation) implies the recognition that handicapping conditions are not fixed in character, they are not the same for each individual, that defects in adaptive behaviour vary from person to person and may be open to different levels of improvement. A process view does not deny an upper limit of a disabled person's potential. Setting unrealistic goals in some cases may be destructive to the very potential that is to be developed.

"Abandoning the assumption that disabilities and handicaps have fixed outcomes should help gain us a world in which there will be increased opportunities for the disabled to develop their potential and an obligation on our part to provide those opportunities. We will not know in advance how great any individual's potential will be. We will learn as we begin to press against those limits. Knowing when those limits are near and avoiding promises that could be enormously destructive are special skills we will all need to learn."[40]

Concerning competence and responsibility, this process view leaves room for a flexible measure of competence, that is to say that competence may vary with time, with individuals and, most importantly, with a task. A task-specific concept of competence implies, for example, that mentally retarded persons may be very competent in a supervised setting and incompetent in an unsupervised one. This does not mean, therefore, that being mentally retarded must necessarily lead to a loss of moral status. As with a physical disability, the degree of handicap will depend on the environment and the lack or presence of necessary support.

The task-specific competency criteria mean that, although a certain world may be lost in terms of the intrinsic dimension of mental retardation, moral status on the extrinsic level is not lost; competency is not irrevocably lost by belonging to the "mentally retarded" category, as is the fixed state view.

3. Self-definition and Independent Living

The concept of "independent living" is still being promoted by disabled people as a consumer movement and it is for this reason that it can be considered as one of the major steps in breaking away from the "eternal childhood status", the paradoxes inherent in labelling and the medical approach developed in Part I of this report.

In a report on "The Movement for Independent Living: Origins, Ideology and Implications for Disability Research"[41], Gerben DeJong goes as far as speaking about the "Independent Living Paradigm" and its capacity to reshape the way in which the problem of disability is defined and how new interventions are developed and policies made. He opposes this to the rehabilitation paradigm that implies a one-way professional/client role whereby the client is always the passive consumer of rehabilitative measures.

He explains the independent living paradigm in the following way:

"According to the independent living paradigm, the problem does not reside in the individual but often in the solution offered by the rehabilitation paradigm – the dependency inducing features of the physician/patient or professional/client relationship. Rehabilitation is seen as part of the problem, not the solution. The focus of the problem is not the individual but the environment that includes not only the rehabilitation process but also the physical environment and the social control mechanisms in society-at-large. To cope with these environmental barriers, the disabled person must shed the patient or client role for the consumer role. Advocacy, peer counseling, self-help consumer control and barrier removal are the trademarks of the independent living paradigm."

Independent living and self-advocacy is a different learning process from that discussed above in "learning to be disabled". Learning to be an active consumer of services means becoming informed about what is most suitable to one's needs, it involves making choices, becoming responsible rather than passively accepting professional advice. The movement for

independent living has set up self-advocacy centres to advise disabled persons of their legal rights and benefits. Through personal, active involvement, a disabled person may become better informed about services, benefits and legislation than his/her professional counterpart.

The independent living movement has encouraged disabled people to become self-advocates, to acquire self-help skills, to learn to take risks and eventually to be able to exercise maximum control over their own lives and the services they use. It tries to replace the traditional "sick role", "impaired role", or "eternal child role" by learning how to be self-reliant and exercise adult citizenship.

Judy Heuman, a participant in the California Independent Living Center spoke in a television interview about how she experienced independent living:

> "Well, I'm originally from New York and I grew up, after having had polio, in a community where there were no support services, where basically I had to depend on my family and friends to help me get up and get dressed and get me around in the community and it was really quite difficult. I was successful at it but I was the exception to the rule. It required that I depend on people and in many cases be nice to people that I didn't necessarily want to be nice to because I needed them for services. Then, when I moved out to Berkeley, California, where there was a programme at that time starting called the Center for Independent Living, it was a whole new world to me to be able to work in conjunction with an organisation whose prime purpose it was to provide services to enable disabled people to live what was being called independently in the community. The word independence to me was a complex term because I knew I physically wasn't able to do a lot of things by myself, so I was wondering what they could be doing for me which would allow me to live independently.
>
> Well, what the services were was that I could call up and get an attendant. I could interview somebody and have somebody come that I would hire to help me get up and get dressed and help me with all my personal care needs. They also had people on staff who could help me with advocacy problems around benefits and they had transportation and a political group that was working on changing systems in the community. It changed my whole life. I really have seen (I'm 34 years old now and I went to Berkeley nine years ago) how very immature I was then. Intellectually I was very mature, but I was on a social level really much more immature because I had never been given the opportunity to take responsibility for myself. It's like being a baby and learning how to grow up and learning how to take on responsibilities for what time I wanted to get up in the morning and what I wanted to eat, how I wanted somebody to cook something, and if I wanted my house cleaned, when and how I wanted it cleaned, just things I never had to take any responsibility for. So it's been a major change in my life."[42]

In a paper on Disabled Young People Living Independently, prepared for the OECD in collaboration with the British Council of Organisations of Disabled People, Dr. Mary John, emphasizes the social change implications of independent living and self-advocacy[43]:

> "The involvement of disabled people around the world in the conscious raising of their own society and the reshaping of that society has marked an unquestionable maturity of the individual and the coming of age of the movement."

At the end of their report, Dr. Mary John and members of DPI make the following remarks about self-advocacy[44]:

> "Acquiring the right to speak for ourselves will obviously not prove easy, especially as long as prevailing attitudes about our dependency remain unchallenged within

government, service professions and educational institutions. Whatever the difficulty, however, disabled people cannot escape the necessity of learning the art of self-advocacy if we are to achieve maximum independence and integration into the community. This means that one of the first tasks on the road to emancipation is to facilitate the ability of each individual to speak for him or herself and to find the appropriate means of gaining recognition for the common voice of disabled people through our democratic organisations. Disabled people have to teach each other these skills, although they may need support, self-advocacy has to come from within the movement. The long hand of professional intervention, however, has even reached into this area. It has now been decided to capitalise on the growing 'self-advocacy' movement amongst mentally retarded people, for instance, and many 'progressive' courses are being mounted by intellectually able people to teach their less able fellow citizens these skills. While we may indeed seek help, such courses cannot be provided for us but have to emerge from the movement. We can no longer remain childlike, powerless consumers of what service providers see as new fashions in our needs.

At a personal level, disabled people are often disadvantaged in their contact with service providers and the general public. Both isolation and acceptance of the right of able-bodied/minded people to be the experts about their lives has given disabled individuals little confidence in their right to become self-advocates. Special education all too often fails to provide disabled students with knowledge and skills about managing their own lives with the assistance of human and technical aid.

Self-advocacy requires much greater knowledge about the nature of disability, solutions to technical problems, information about rights and the law and confidence in expressing one's views. Many organisations of disabled people are concerned about the state of knowledge amongst their members and some have started discussion groups as well as consciousness-raising sessions. There is also now the real possibility of representatives from organisations of disabled people joining with non-disabled service providers who do have expertise concerning the provision of aids, the structures of local government and the details of the law, etc., to collaborate on self-advocacy programmes for their members. This is appropriate help and support for the self-advocacy movement. In this respect there are now new exciting possibilities for the development of genuine support systems in which disabled people exercise controlling influence over the direction of collaborative programmes while at the same time service providers gain satisfaction from a more fruitful use of their expertise.

It is clear that individual self-advocacy cannot be achieved without the collective support of other disabled people. The building of organisation of disabled people, therefore, looms as an urgent task. In this task, we once again face enormous problems. Relatively, very few disabled people have the confidence and skills for organisation building. Here too, then, government and the statutory and voluntary organisations can play a vital role in supporting our efforts."

The main role of organisations controlled by disabled people in promoting self-advocacy lies in their ability to encourage individual confidence, to facilitate educational and training schemes in self-advocacy and to act as a channel for communicating the views of disabled people to the national, state, regional and local authorities. Such organisations can also provide democratically-elected advocates to sit on all appropriate committees where decisions affecting the lives of disabled people are made.

In the final analysis, the "right to be disabled" requires recognition of genuine rights concerning self-advocacy. Legislation prescribing 51 per cent representation of disabled

people from organisations of disabled people on all committees and bodies which are substantially concerned with disability issues will go a long way in finally ending the myth that disabled people are "eternal children".

Although it may not seem obvious, independent living and self-advocacy are today essential issues in the lives of people who are mentally retarded and severely disabled. The means for attaining these goals, however, imply certain difficulties since persons with mental disabilities are less likely to claim their rights and become organised in pressure groups.

The negative effects of labelling and the debilitating consequences of institutionalisation, although they have applied to different types of handicaps, have weighed especially hard on persons classified as mentally retarded. The first wave of criticism of such practices was based on the idea that the "individual needs" of mentally retarded persons were not being met. Therefore, innovative practices tried first of all to identify and meet such clinical needs. However, it was (and often still is) a question of professionals knowing and defining these "needs". Persons classified as mentally retarded are not considered capable of defining their own needs. They are the most firmly grounded in the "eternal childhood" myth.

Self-advocacy, therefore, is a real challenge to the stereotyped view that persons classified as mentally retarded cannot speak for themselves. The self-advocacy movement began, in fact, in the early 70s in local self-help groups. It began in the United States under such groups as People First, The Fifth Stand, Project Two; Sweden, Canada, the United Kingdom and Australia followed. These groups work on raising the self-esteem of their members, train them in communication and advocacy skills, and try to alter public attitudes and service provisions. In addition to consumer conferences, self-advocacy groups stress training in the rights and responsibilities of adulthood, voter registration, training in communication and assertiveness skills, and ways of working with other advocacy organisations.

Dr. Rosemary Dybwad[45] observed these groups and concluded that members gain self-confidence and "experiences which will prepare them to make choices, to assume responsibility, to participate in the life around them".

Despite the development of "self-advocacy", persons classified as mentally retarded need to rely on a "mediatory" mechanism to ensure that their rights and interests are met. Stanley S. Herr, in "Rights and Advocacy for Retarded People"[46] enumerates the different mediators to be considered as advocates of the interest of mentally retarded persons:

> "Family advocacy is a critical support for both retarded children and adults. They, more than other children, need supportive adults to prepare them for a life of growing independence as well as interdependence on others. The parental role is considered by the US Constitution to include 'a vigorous assertion of the child's interests, since those who nurture him and direct his destiny have the right, coupled with the high duty, to recognise and prepare him for additional obligations'. Parental involvement in educational planning is also promoted by current legislation. It is obvious that those young people whose parents are active and knowlegeable about appropriate education have a better chance of access to proper schooling and support services. The underlying issue is that of opportunities for parents to learn of those rights or to receive basic advocacy training."

Many retarded persons, especially those in institutions, cannot rely on family support. Parents pass away or many (especially those whose offspring have lived in instititutions) are not effective advocates for their handicapped children's rights because they have been "erroneously led to believe that their children will not be able to lead meaningful lives".

Another form of mediation is "friend advocacy", a form of one-to-one volunteer assistance designed to meet the emotional and instrumental needs of a given protégé. In 1972, Wolfensberger defined the citizen advocate as a "mature, competent citizen volunteer representing as if they were his own, the interests of another citizen with unmet needs for practical or emotional support". The problem, of course, is the lack of sufficient numbers of such volunteers.

Disability Rights Advocacy is when advocacy specialists deal on a regular basis with the particular needs of those receiving human services on the level of both systemic and individual cases. Herr's criticism of this form of advocacy is "the disparate nature of its functioning and the tendency to overlapping, i.e. lay advocacy, systems advocacy, mental health advocacy, etc.". Because their primary purpose is lobbying for new laws and monitoring service delivery systems, they tend not to have the resources to pursue individual cases of low visibility on a systematic basis.

Human Rights Advocacy committees composed of volunteers with lay and professional backgrounds offer a forum for monitoring the implementation of disabled people's legal and human rights at a local level. The mandate of such committees will vary with their specific charge but they can make enquiries into abusive practices, provide informal resolution of disputes and offer policy recommendations. Often human rights committees see themselves as both arbiters and advocates and as such may cause tension when professionals' claims to clinical or administrative autonomy clash with the committee's interest in protecting the rights of consumers.

However, as with other volunteer groups, whatever their role, given the constraints of limited staff, training and time, these committees are only a link to and not a substitute for independent full-time client advocates.

Another issue is whether advocates are internal or external to service delivery systems. Internal advocates are known by such names as human rights officers, rights advisors, ombudsmen, etc. They tend to perform investigative roles inside their agencies, counsel and educate other employees on rights-related matters and otherwise try to support the rights and dignity of residents. Herr's criticism of such advocates is that in most states service delivery systems are reluctant to commit resources in this way. Therefore, such services are sporadic and not always reliable in notifying residents of their rights.

A high credibility advocacy system is the legal one; however, there is as yet little involvement in the legal profession to help retarded people. Herr claims that it has been difficult to involve the traditional private sector and that legal advocates in the mental disability field are mainly drawn from non-profit organisations, public interest law projects, protection and advocacy agencies, legal-aid offices and academia – along with some private and government attorneys.

According to Herr, litigation, regarded as the "cutting edge of reform", has not been sufficiently used to protect the rights of people classified as mentally retarded. He states that one federal court has officially recognised legally-trained advocates as "an absolute necessity for protecting the legal rights of people labelled mentally disabled who are subject to institutionalisation or deinstitutionalisation".

He stresses the importance of the advocate's independence and of his/her separation from service providers, both administratively and financially. In fact, this independence is required by the Code of Professional Responsibility and is essential to enhancing client control of the advocacy function.

He states:

"The legal advocate's role is to be a zealous partisan of the client's interests and goals, not a paternalistic surrogate or a detached counsel for the situation. This role not only

comports with prevailing expectations for attorney-client relationships, but affirms the very dignity of choice and risk-taking that care systems are supposed to encourage for their clients. Here again, advocacy officers are best equipped to train and guide lawyers and legal advocates on the hazards of slipping out of role, of usurping the role of guardian, judge or ombudsman or of simply signing up as another member of an interdisciplinary 'helping team'."[47]

He warns against the tendency to overlook the fact that persons classified as mentally retarded can express an understandable preference and can provide counsel and assistance in ascertaining their wishes and interests. Exceptions to the rule, such as profoundly-retarded persons or those who don't have language, are in fact relatively few as compared to those who can indeed benefit from client-guided and client-directed representation.

V. PRINCIPLES INTO PRACTICE

The preceding chapters have tried to discuss some of the main issues concerning the acqusition of adult status for young people with disabilities. It was also pointed out that traditionally institutionalised rehabilitation measures, whether in education, vocational training or sheltered employment have tended not to encourage autonomy and independence and have tended to maintain disabled young people in a state of childhood.

More innovative practices are increasingly becoming aware of the importance of identity issues such as self-esteem, autonomy, independence and adult status. The present section will briefly outline some examples of practices where the development of adult status is a central concern.

1. The Genova Challenge – Adult Status Through Work for Mentally Handicapped Youth[48]

The *Istituto San Paolo di Torino* is one of Italy's largest banks and the main branch, in Genova, an impressive edifice from the end of the last century, is situated in the centre of the Old City.

Mr. P, a young man with Downs Syndrome, has been working in the mail order department for three years. He has been a full-fledged employee for two years and no longer needs the support of the integration team of the local health unit *(Unità Sanitaria Locale 12)* nor the special grant that was allocated to him for one year while he was undertaking job training. When the bank announced that they were satisfied with his work and proposed to hire him on a full-time basis, he was moved to tears – he telephoned his family immediately – "I am crying, but it's good, it's good.".

The Personnel Director expressed the bank's satisfaction with Mr. P's work. He added that since Mr. P has been working with them, they have reduced the post from three to one and a half persons. Mr. P works full time with someone who is half time. He carries out the same work as his "normal" colleague; he may work more slowly, but he works more continuously and more precisely than other employees.

From Mr. P's point of view, the experience is excellent since after one year of trying out whether he could actually carry out this job, he has become a full-fledged employee with the same salary as others.

Before coming to the bank, Mr. P spent some years in a sheltered workshop where he was considered as severely handicapped. He was thought to be incapable of working, and was then temporarily placed in an on-the-job vocational training scheme. He was then able to obtain a special grant which will be explained later on.

The employment of Mr. P at the *Istituto San Paolo di Torino* is the result of four years of intensive work with public and private enterprises in Genova concerning the employment of

mentally disabled young people. This has been, and is being, carried out by a specialised team of social workers, vocational training teachers and one psychiatrist (nine members in all) belonging to the Regional Health Service.

Banks, usually considered to be the safeguards of conservative policies, were the last to be recruited in the process of trying to open employment for mentally disabled workers in the Genova labour market. In 1981, a meeting of directors and employee unions of all the main Italian banks was held by the Mayor of Genova to discuss the feasibility of the employment of mentally handicapped workers in banks.

All banks were in agreement with the principles. The team then began working with bank directors and it was the director of the *Istituto San Paolo di Torino* who then accepted to try out such an experience with the team and Mr. P. Since then, a number of other banks have also shown their willingness to make a concrete trial.

The employment of Mr. P by a prestigious bank is not an unusual event in Genova. In the last five years, 200 mentally disabled young people have been successfully employed by both private and public firms. To cite but a few: Marconi, a multinational electrical company with 1 400 workers has employed five disabled young people. Mr. S works in the dispatching department and fills the orders that come in for small parts. The task is complex and necessitates a good memory, which is one of Mr. S's strong points, despite the mental retardation and diagnosis as psychotic. He came to Marconi from a sheltered workshop four years ago. His supervisor is very pleased with his work and is able to relate to him in a non-patronising way.

Mr. L is severely mentally retarded and has worked for the last three years for a Brignola Paint Manufacturer. He is at the end of the production line and stacks paint cans for packaging. He must remember to shake each can before putting it in boxes. He also does other jobs to help his colleagues when necessary. He is well accepted by his fellow workers who take pleasure in witnessing his progress.

The public service also employs disabled young people. Mr. G works in one of the central offices of *Ufficio Notizie* (Public Announcements). He also came from a sheltered workshop. Diagnosed for mental retardation, he is additionally handicapped by unusual facial features. His job is folding and packaging posters with five other colleagues. Mr. G performs much better than expected; he is very precise and attentive and works more carefully than other workers. The director finds the experience so positive that he is thinking of employing another disabled worker.

The insertion and support of mentally disabled young people in open employment is made possible by a highly organised and co-ordinated multi-disciplinary team. The team includes instructors formerly working in sheltered workshops, with expertise in work organisation and techniques as well as professionals, such as a social workers and pedagogues with experience in social health services. The team is headed by a psychiatrist who is responsible for its functioning and is administratively attached to the USL, the local health unit.

Supporting the integration of mentally retarded workers involves complex co-operation at different levels of local and municipal politics, as well as close work with employers, unions and parents. This aspect will not be described here in detail, as it has already been related elsewhere[1]. However, the positive and representative nature of this co-operation between the different partners of integration is well illustrated in how various obstacles have been overcome, including contradictions found in the law. The ambiguity of the quota system has been a concrete barrier for integrating mentally disabled workers since they were not originally included in the 15 per cent of disadvantaged persons to be integrated as stated in the Law 482 of 1968. Just as in overcoming other barriers, the collaboration between local politicians, administration and the professional team was effective in changing the

regulations. A national conference was held in Genova, where representatives from the Ministry of Labour, the National Employers' Associations, top union leaders, Parents' Associations and the media were invited to discuss how the integration of mentally handicapped workers was, in fact, possible. With the support of concrete and successful practices, the conference was able to make strong recommendations and the regulations were indeed withdrawn.

Adult Status and Employment

Besides the factors already mentioned that contribute to making integration in Genova innovative, it is the deep concern with the mentally handicapped person as an individual and his/her identity as a person with the potential of becoming an adult in both the social and psychological sense, that has motivated the choice of including the Genova experience in the report concerning adult status.

Practice, close observation and social as well as psychological analysis of the subjects involved has resulted in a dynamic comprehension of why integration in open employment of mentally handicapped young people is such an important factor in promoting their acquisition of status and identity as an adult person. It is in fact this maturational process that is seen as the *raison d'être* of integration in employment.

It is well known that people with disabilities of a mental nature, especially mental retardation, have traditionally been deprived of civic rights and status. This fact has probably played a major role in influencing public opinion and attitudes concerning their incapacity to work. Aside from any constitutional disabilities, people with mental retardation have tended to be deprived of a social/adult role in society. Although the move to integration has increasingly favoured the acceptance of children with mental handicaps within the mainstream of normal schooling, the transition from a childhood/school role to an adult one is much more difficult.

Transition to adult life and status in society is not easy for most young people. Adolescence is a difficult period wherein important biological changes and emerging sexuality need to be combined with the gradual acquisition of social responsibilities in order to construct an identity as a functioning adult member of society. The Genova team believes that work in open employment is a fundamental step by which mentally disabled people acquire a social "positional" role as opposed to an infantile, "personal" one:

> "In the first place, work stimulates a strong motivation towards adult status; a work setting does not have the infantile characteristics of the school and the sheltered workshop and is concerned with the exercise of a real status which is carried out according to operative necessities giving many concrete advantages."[49]

Experience in Genova has shown that the best setting for integration from the point of acquiring adult status (positional role) and promoting mature relationships is the large factory. Sheltered workshops are specifically seen as encouraging habitual infantile behaviour because the personnel are there "*for*" the benefit of the handicapped person therefore distorting the normal working relationships "*with*" colleagues that can be established with those persons who share the same reality.

When evaluations were made of the success of integration in terms of adaptation to work, its rhythm and requirements, and of socialisation, that is, the capacity to undertake active social responsibilities and the ability to achieve working efficiency, the greatest difficulties were found in the area of socialisation and adaptation to the work climate. Learning to work efficiently, on the other hand, was not found to pose a problem provided that tasks were

presented in sequences and that the work was concrete and strongly connected to reality and didn't require our understanding of abstract thought.

Montobbio and his team write:

> "The immature relationships of a handicapped person, his desuetude concerning status and rules – elements connected more with previous experience than with disability – have often caused problems to arise, although from the point of view of learning to work, because the work environment was valued previously, no important difficulties were found. A mentally handicapped person, according to our experience, can acquire working sequences which are quite complex, although finding understandable difficulty if his work requires the elaboration of an excessive quantity of information."[50]

On the other hand, the extreme importance of personal and emotional relationships may interfere significantly in the mentally disabled person's learning to work and his/her functioning in an enterprise. Therefore, the person tends to learn or not learn, depending on the personal model with whom he/she is in contact and not in relation to the requirements of the environment. The Genova team has found, therefore, that the more a disabled young person is placed in a situation wherein the individual, emotional relations are dominant (family, sheltered workshop, etc.), the less he/she will be able to acquire a worker's role and the more the vicissitudes of his emotions will interfere with his learning to work. These considerations are taken into account when placing young people in enterprises. It has been remarked that some mentally disabled persons, especially those who have a long history of institutionalisation and are very dependent emotionally, are more successfully placed in small family enterprises than in factories. For this type of person, the emotionally charged model is the only means of identifying with a worker role. The team observed, however, that in such cases where the personal model is dominant within the working relationship, the individual matures more slowly and tends to develop less personal autonomy.

The Genova team feels that a deep understanding of the personal and emotional world of mentally disabled youth is essential for integration to be successful. Placement without such reflection can indeed be dangerous. Although slow intellectual development may be related to biological factors, emotional immaturity needs to be related to early childhood experience, especially the tendency for families to react to the handicap by overprotecting such children and not attributing to them responsible roles that normal children usually hold in the family and society. Mentally disabled children then become doubly handicapped. This dependent relationship is then carried on into adult life and plays an important role in provoking rejection in the "normal" milieu, i.e. in the workplace, at school, etc.

The kinds of manifestation characteristic of such dependent behaviour are often scarcely bearable for fellow workers and result in the termination of the experience. This is why the team is very careful in judging the potentials of the situation – both from the characteristics of the milieu as well as the personal capacities of the young person. It is this initial prudence that has resulted in a 90 per cent success rate of all the 200 youth integrated. They found a very high tolerance on the part of workers concerning slow comprehension of the rhythm of work – but low tolerance concerning the manifestations of infantile, dependent relationships. The Genova team feel it is especially important to monitor the personal dimensions of the integration in work, especially since in our cultures these aspects tend to be underestimated in the domain of the labour market where pedagogical efforts are concentrated primarily on the acquisiton of skills rather than the development of emotional and personal maturity.

Integration in a normal workplace ascribes an important role to the disabled person, perhaps the first social role in his/her life – that of worker. This role is a major buttress of adult identity. Within sheltered, institutionalised settings, this role is not a real one since the

disabled person is often not expected to conform to real rules and responsibilities, as is often the case in school integration as well. This exemption from social rules, duties and responsibilities results in serious problems of personal maturity and identity. This is why the Genova team consider that working with the family at the same time is of great importance, so that the acquired social role is also respected and maintained in the home.

Montobbio writes:

> "Initial employment causes a revolutionary experience for mentally handicapped persons, that is the possibility of having a role, a container of identity in the area of normality. However, this integration has its limits, given the history of segregation that is still to be overcome in our present societies. A mentally deficient person, when he becomes a worker, does not have complete access to other typical elements of adolescence, in particular, to a real freedom of decision, to an effective socialisation during his spare time and not even to the typical defence mechanisms of adolescence (opposition, sublimation, idealisation, etc.).'

He goes on to say that often in situations outside the workplace, when the mentally disabled person tries to express his independence in decision-making and organisation, albeit in a clumsy way, he/she is counteracted, limited and put down as if an adult role outside the workplace were prohibited:

> "He acquires a 'self' of an intermediate type containing extraordinary, positive and reassuring elements because of being a worker, but also painful aspects because there is not access to a status which is sufficiently integrated on the place of experience and relationships, particularly the affective and sexual ones. In conceptual synthetic terms, the image that a mentally handicapped person has of himself in our opinion is of the 'handicapped person who works' rather than of a 'worker who is handicapped'."[51]

Thus, a "working role" may resolve some problems of adult status for a mentally disabled person, but leaves many others, in the area of effective socialisation, unsolved. Montobbio recommends that: "from the educative aspect, it is necessary to make known that it is in the earlier ages of life, in the 'attribution of roles' in the family, at school and in spare time, that the road towards the acquisition of better possibilities of real social integration in the world of the adult and, indirectly, of a less painful identity is to be found".

2. Individual Case Management as a Support for Personal Growth Towards Adulthood

The next example is an extract from the case history of Heather, a young adolescent girl of nineteen who has Down's Syndrome, as written by her case manager, Dr. Gaston Blom in January 1981[52]. The reason for including this case history as an illustration of practices regarding adult status is because it represents a unique approach to the emotional and personal development of a young person classified as mentally retarded, and it relates the significant progress towards adult living and independence that resulted from two years of individual counselling.

Persons classified as mentally retarded are traditionally not thought of as being able to benefit from any kind of in-depth counselling or therapy on a long-term basis; this is because it is felt that insight is related to cognitive capacities of an at least average level.

Blom writes:

> "Most textbooks present a limited and stereotyped view of Down's Syndrome. One typical, current text states that emotional disturbance in retarded persons is more a social

phenomenon than an intrapsychic problem and that it may be more effective to consult or train teachers, foster parents, or institutional attendants than to try to undo, in psychotherapy, damage resulting from misdirected upbringing. ... In choosing the least restricted alternative, we must question the preconceptions and stereotypes which affect our professional behaviour. In this case, one must ask: are personal strength and insight correlated with measured intelligence? Does cognitive capacity determine all behaviours in a mentally retarded person? Does mental retardation necessarily narrow the range of remedial alternatives when a psychological disturbance is present?"

Dr. Blom did in fact go beyond stereotyped conceptions of what was possible and opted for what he called the "least restrictive alternative", that is, to recognise that Heather, in addition to concerns related to her handicap, was upset by her inner emotional pressures as are many other adolescents and therefore was entitled to individual therapeutic help, as another adolescent would be.

> "For two years I shared Heather's inner feelings about herself and her past and current experiences with the world of school, work, buses, home and church. I tried to be helpful in dealing with many realistic problems and issues. But these endeavours would not have been possible without the support and confidence of her parents. On many occasions her parents were accused by professionals of not accepting Heather's limitations. They were also frequently questioned about the suitability of psychotheraphy for Heather."

Despite a very negative classification of Heather, seeing her only as a "trainable rather than an educable mental retardate", as well as suspecting her of being psychotic, Dr. Blom agreed to see Heather:

> "I was surprised that Heather was able to verbally communicate so many concerns and problems to the psychologist. I wondered why the positive findings from psychological testing were discredited as being responsible for difficulties and for interfering with practical, concrete adjustment skills. I also wondered what kind of psychiatric evaluation and possible psychotherapeutic treatment had been expected.
>
> When I first met Heather's parents, they were frightened and confused by the disturbing interpretations and conclusions of the school psychologist whom they stated had not clarified the actual nature of Heather's homelife and current school adjustment. While her academic grades in special classes were C's and D's during the academic year, Heather received satisfactory ratings in six different work experiences. The parents had sufficient personality strength to question the psychological interpretations. Heather's mother knew her daughter was sad and troubled, but she had every basis to doubt that Heather was psychotic."

The above illustrates the significant difference between a standardized, labelling approach and the "individual case management" attention that Dr. Blom gave his client, especially his willingness to pay attention to her personal needs in all their complexity. The important role of strong, advocate-oriented parents is also underlined as being essential to resisting the labelling approach and its consequences.

Unfortunately, it would take too long to relate the entire story of Heather as told by her therapist. However, it may be said that their two years of work together was highly positive. Heather was able to get out of her depressive state, obtain a job and maintain it, get married (although this aspect was not simple since her husband's mother refused to consent to an adult independent status for her son, also mildly retarded). Heather left her parents and lived on her own in an apartment and managed to live as independent a life as possible. Dr. Blom closes

with the following statement about having taken an alternative stance in terms of his work with Heather:

> "Human service professionals have enormous power and influence over those defined variously as handicapped, ill, clients and patients. Such power is the result of many forces: the knowledge gap between the server and the served. The sanction society gives to the authority of the professional, the nature of professional training and role induction that fosters the concept of authority, and the limited alternatives that many professionals offer ... how much true, appropriate, mutual participation exists between the professionals and the client or his/her representative in decision making that affects the life of the client? In my experience, this type of participation tends to be more unique than usual. It stands in contrast to the more usual provider of services who makes most decisions in the authority stance.
>
> I found the alternative, democratic stance difficult, yet helpful and reasonable. It was possible to have feelings and yet be objective and to take actions when they seemed called for. I am not advocating free license to divest clinical professional thought. Rather, I do challenge its rigidity and the validity of its practices when they are reinforced by questionable knowledge and already biased experiences in relation to mental retardation.
>
> Heather advanced in a world that tended to question and even to oppose her rights to as normal a life as possible. In presenting this story, Heather, her family and I hope to make the issues in the least restrictive alternative more vivid to those who experience handicaps and to those who are their helpers. As Heather stated in one of her letters: '... and Wayne will be thinking about you when you give my story and I personally thank you for listening to me and knowing my ups and downs, and helping us both with our problems and how to face the world. Love, Heather and Wayne.'"

3. Coming to Terms with Identity as a Disabled Person

Becoming an adult is a gradual process of learning which involves coming to terms with one's own strengths and weaknesses and knowing what one can or cannot do. As pointed out earlier, becoming an adult for young people labelled as mentally retarded can be even more difficult than for persons with other disabilities. The precedent example illustrates that part of the difficulty for mentally retarded young people lies in the lack of knowledge about the nature of their disability and therefore the additional handicap in learning who they are and what kind of adult life they can look forward to.

> "To be able to deal with our problems, we must realise that we are mentally retarded, its as simple as that. I had to fight to learn that. You couldn't talk about it at home. You still cannot do that. It is a kind of hot potato, everyone seems to be avoiding it. That's what makes it so damned hard. You have to force them to talk about it. It is just the same in our boarding homes and institutions. The subject is avoided by the personnel. They just won't tell us the truth. Has anyone told you, Mary, that you are mentally retarded?"

This excerpt, taken from a paper on Adult Status for Mentally Retarded Youth prepared by Dr. Mårten Söder[53], is quoted in this report as an exemplary case. The material is taken from a week-long group discussion of five mentally retarded young adults who discuss freely their life experiences. It is not possible to include the full paper in this chapter and the

following excerpts explain the activity, its *raison d'être* and how it is carried out in Sweden.

M: "I couldn't make it in the regular school. I wasn't able to make the ninth grade, they told me. I was placed in the special school for mentally retarded. Reading and writing were too difficult for me."

LG: "Yes, but did you learn why this was difficult?"

M: "No, no one told me."

LG: "They didn't explain to you why all this happened. It is just typical. We are not informed. But others are informed about us. I think we have the right to be informed too."

O: "I don't really know what mentally retarded means. I guess many of us don't. Nobody tells us about it."

LG: "Isn't it some kind of impairment? A damage you get at birth or something like that?"

S: "Yes, I asked my mother what it was. She told me my brain was damaged when I was born."

O: "Retarded means that you are backwards in some way. You lag behind, far behind in school. Maybe it is because you are lazy, I don't know. It is really difficult to understand."

LG: "Earlier it was called subnormal. But now we call it retarded. Your intelligence is impaired. You have difficulties in learning new things. Some mentally retarded have other handicaps as well. You have problems in keeping up with others in school, it is more difficult for you to learn. It's as simple as that."

GB: "It takes more time for us to learn than for others. We also have difficulties in following others. When they talk about things you sometimes don't know what they are talking about."

M: "I have problems with papers I have to sign. Sometimes they tell me that I will be allowed to move to an apartment of my own. But then there are all those paper problems, tenancy agreements and things like that. It makes me feel very insecure."

G: "When you go shopping it can be very difficult to know how much money you should have in return. I am not very good at counting. You have to look at the shop assistant, but you cannot be sure she is right. Usually I ask if I have the right amount back. But even if they say so, you cannot really know that it is true."

LG: "I know. You often feel insecure and helpless in situations like that."

LG: "But is it impossible to train these weaknesses? By training you could perhaps learn and be more confident? Then you would not have to depend so much on others."

GB: "I think that would be a good idea. I feel so insecure doing things I cannot really manage."

O: "Some people are brighter than you are. You just cannot keep up with them."

LG: "I think we have to accept that we can't keep up with others. But there are some of us who won't accept that. If you say the word "retarded" to them, they get angry. Some retarded persons refuse to accept that word."

M: "Well, I am not disturbed by that word..."

S: "I think "handicapped" is a better word."

LG: "But we can't change the word just because society will not accept us. That would mean that we have lost. This must not happen."

The quotations above are taken from a discussion between five moderately retarded adults. It illustrates the major problem for these persons in striving to reach adult status: how to realise and cope with the fact that you are mentally retarded and its social consequences. As the discussion shows, the nature and handicapping effects of being mentally retarded are seldom dealt with in a straightforward way. Rather we tend to avoid raising the issue when dealing with retarded persons. Although disguised in a well-meaning attitude (we don't want to "hurt" them), this probably has something to do with our own fear of being disabled. But the way we treat retarded persons, anyhow, tells them something about the nature of their handicap. Our way of concealing the true nature of their handicap to them is a sophisticated way of overprotecting them, that tells them that they are not able to understand and deal with the most socially important of their personal characteristics. This treatment lessens their capability and their motivation to take full responsibility for their actions and to live as an independent adult. It is, as someone has put it, like trying to rehabilitate a blind person without telling him that he is blind and what that means.

The discussions were arranged by a psychologist and a social worker. Together with the group they spent a week talking about their handicaps and their experiences of difficulties in social life. The discussions were recorded on tape. Later, the material on the tapes was written down, edited and published in book form. The tapes and the book are used as study material for other groups of mentally retarded adults. Several such groups have been formed, and they use this material to get started in discussions about their own problems and experiences.

The latter part of the 1960s saw the birth of new ideas and ideologies in the field of mental retardation in Sweden. Propelled by the economic expansion, a growing optimism for retarded persons with regard to the possibilities of living a normal life was articulated. Institutionalisation was attacked. Integration was formulated as a leading principle for services. The principle of normalization, founded on the reaction against total institutions, spelled out the concrete meaning of a normal and independent life for the mentally retarded.

In this new perspective, the mentally retarded were seen as equal citizens, with a right to living conditions that were, as far as possible, similar to those of the population in general. Associated with the principle of normalization was a strong feeling that the retarded had the right to independent living, including the possibility of influencing their own situation. The systematic overprotection and powerlessness most obvious in traditional institutions stood out as an antithesis to such independent living.

An active proponent of the new ideas was the organisation for parents of the mentally retarded. One of their paid officers, Bengt Nirje, was the one who first gave a coherent formulation of the principle of normalization and its full consequences. He also advocated the idea that the mentally retarded should be given a voice of their own within the organisation. Until then, it had been "the organisation for mentally retarded children". Of course, many parents had adult, mentally retarded children. But in their view, they were also children in a social sense. They were not expected to speak for themselves.

Bengt Nirje and another paid officer of the parents' organisation, Ann Bakk (who several years later was to initiate the discussion groups referred to above), started organising special conferences for the retarded, often at the same time and place as the meetings of the parents. Although not very popular among the majority of organised parents, this was a breakthrough when it came to demonstrating that retarded adults could speak for themselves. At the "youth

conference" (as they were called in line with the refusal of many persons to see them as mentally retarded adults), they discussed their own situation and came up with a list of demands for better services.

Another initiative of Bengt Nirje and Ann Bakk – stemming from the same ambition to promote independent living – were the "social clubs" for mentally retarded and non-retarded persons. The immediate purpose was to break the isolation of retarded persons living with their parents. The groups met a few times every month. They arranged parties, went to movies and theatres, went for picnics and so on. To these social activities were added some that were more clearly intended to function as social training. Such activities included going to the post office, buying train tickets, etc.

Many parents who heard about the social clubs called and wanted their children (i.e. their adult, mentally retarded children) to join a group. In order to recruit more non-retarded persons, a "recruitment meeting" was held at the university. The number of attendants among the students exceeded all expectations and many were willing to participate in integrated social clubs with mentally retarded. This was at the end of the 60s, when even the not so revolutionary students took quite an interest in social problems and this kind of social reform activity.

More social clubs were started. The amount and nature of activity of course varied very much.

In some of the groups, however, non-retarded participants started to spot a problem. Many of the retarded participants came to the groups from clearly overprotected environments. Some were not used to social interaction at all. Others were very defensive. Suddenly they had to face real-life situations that had never confronted them before. This made them insecure and unsafe.

It also resulted in a structure in the groups where the non-retarded persons stood out as leaders, or even parental substitutes. They had to take all initiatives, to arrange social training situations, make important decisions and so on. This was clearly in opposition to the basic philosophy of equality on which the groups were founded. In most groups, the problem was not recognised as such. The leading role of the non-retarded and the powerlessness of the retarded was hidden away under seemingly democratic forms of decision-making. But in some clubs, non-retarded participants recognised the problem, felt uneasy and tried to talk about it in the group. But this turned out to be very difficult. To deal with it, you had to go to the root of the problem: the very fact that some participants were retarded and others were not. Starting discussions on this subject caused many frustrated reactions from the retarded participants. Some refused to talk about it at all. Others reacted emotionally, were clearly stressed and felt threatened by the whole subject. They simply had no way of handling the issue.

Some parents also reacted strongly against this type of activity. Some of them even stopped their adult children attending the clubs. They wanted them to have a nice time in the clubs, but not to have them upset by serious discussions about their own handicaps.

In the 70s, the clubs more or less disappeared. The radical students grew up and were occupied with their own careers and families. The initiators, whose enthusiasm had been the motivation for much of the activity, went into other occupations. Ann Bakk became a psychologist. But she kept in contact with some of her retarded friends and also put her professional interest into this area. More and more, she realised that the problems for many mildly and moderately retarded persons were founded on the fact that they never got a chance to learn about, realise and emotionally handle their own handicap.

This is, in short, the background to the initiative to get five retarded people together, to talk about their handicaps and their own experiences in their situations and to use this as study material for other groups.

As late as the mid-70s, when this took place, the idea of the mentally retarded talking about their own handicaps, was still a controversial one. Although a number of people were talking about the need of the retarded to acquire a realistic "handicap consciousness", many did so as though identity and self-image was something that professionals or parents could give to the retarded as a precious gift. But the idea behind the study material was not to give consciousness to anyone, but to give retarded persons the possibility of creating their own consciousness; and that was, and still is, a controversial idea.

Working in discussion groups, from which material has been used to illustrate how retarded persons view their own situation, is a method that has been applied in many similar groups of mentally retarded persons. The purpose of the groups has been to stimulate discussion about themselves, their problems and sorrows, as well as their expectations and dreams, within a safe atmosphere. Learning about the nature of your disabilities and facing the consequences is supposed to help you deal with situations in daily life. Getting a realistic picture of your shortcomings and potentials will help avoid certain situations and deal more energetically with others.

The purpose is to learn about society and your place in it. The situation of the retarded is just as much dependent on the reactions of society as on the individual disability. By listening to others, comparing their experiences with your own, you can more easily realise that. Seeing the relation between your own disability and your environment also makes you more able to make demands on the environment. Another important objective of these groups was, and is, to make the retarded capable to fight for themselves against discriminatory conditions in society.

Based on the experiences from several different groups, some guidelines for the work have been issued. They give some idea about the nature of activity in the groups and also, indirectly, what kind of problems they might run into. The following are examples of things considered important in those guidelines.

How to use the material: The basic function of the material (tape and book) is to stimulate the participants to talk about their own problems and to reflect upon their own experiences. It is hoped that they will recognise the things that are described and the situations that are discussed, and that this will encourage them to talk and associate freely. It is particularly recommended that the material should be used in a way that is adapted to the needs of the single group. The material itself – its structure and its content – should not be allowed to direct the discussions on account of the experiences of the participants.

Composition of groups: It is recommended that groups should not be too big. Five participants is seen as enough, possibly a few more if there are two group leaders. The participants should be mildly or moderately retarded adults. It doesn't matter where they live or work, but heterogeneity in these matters has been shown to stimulate discussions and facilitate the exchange of experiences. Groups composed of too many persons with emotional problems don't function well. The same difficulties arise if most of the participants have a need to deny their disabilities – not accepting that they are mentally retarded. Participation must be voluntary. When invited to participate, the retarded should be honestly and concretely informed on what it's all about. Those hesitating should be persuaded not to participate. Groups should meet regularly within short intervals over a long period of time. Once a week during half a year is recommended as a minimum.

Group leadership: The groups should be led by one or two non-retarded persons. The most important criterion for a leader is that he/she is interested in the situation of mildly or moderately retarded persons and has reflected on the issues raised. It is also important that the leaders are prepared to listen to and learn from the retarded participants. It is recommended that an inexperienced leader has some kind of back-up, a psychologist or experienced social

worker with whom they can discuss what's happening in the group. The leader should not be in a position that makes the participants dependent upon them in their daily lives. They should not work in the services where the retarded is a client. That could stop the participants from voicing negative reactions and feelings towards personnel and service arrangements.

Group atmosphere: A programme should be agreed upon in the first meeting. It should stipulate when and where to meet, for how long, rules for attendance and so on. The participants should be encouraged to participate as much as possible. Obligation to observe silence about what's happening in the group is very important. What is said should not be discussed with anyone outside the group. Participants must be made aware that they mustn't tell any outsider what is said or how participants act in group sessions.

The leader should encourage participants to relate to each other. Very often participants see the group as a study course and view the leader as a teacher. They address all questions to him/her and don't really listen to each other. One of the first tasks of the leader is to break this and stimulate participants to discuss with each other, to listen to and respond to what other participants say.

Permissiveness for showing emotions in the group is necessary. Emotional reactions should not be avoided and participants should be encouraged to express them as clearly as possible. This way the participants will feel safe, realising that their expressions are permitted and understood.

Getting the mildly and moderately retarded to discuss their handicap and its consequences is sometimes seen as controversial. Encouraging them to articulate their criticism of services and treatment caused many critical reactions.

The arguments put forward against this kind of activity are usually centred around three partly-conflicting reasons.

The first argument says that mentally retarded are unable to speak for themselves. The nature of their handicap makes it impossible for them to articulate their own experiences.

The second argument states that when the retarded speak for themselves, they are just repeating what someone else has taught them to say. Others put words in their mouths that they are repeating like parrots.

The third argument accepts that the mildly and moderately retarded can speak for themselves, but they represent only a small section of the retarded population. Thus, they are not at all representative of the total group of mentally retarded.

We will not argue about these points here. But we will put them against what the retarded persons in the group quoted earlier said:

GB: "It is important that you put your foot down sometimes; that you can defend yourself. That's important, isn't it?"

M: "Yes, sometimes you need to be brave. You have to tell them when something is wrong, although you don't want to. You have to. Even if you know you are making them angry."

O: "I feel proud that I am able to oppose them. For forty-two years – that's a long time – I have been trying to get out of the institution. I wonder how many could take it that long ... who would keep on fighting, I mean."

LG: "It is something to be proud of – that you are fighting. We've got everyone against us. When we start making demands, they say people put words into our mouths. They believe we are so easily influenced that we cannot speak for ourselves, but we are not. They don't think retarded persons can come up with any good ideas themselves. We have the same problem as many other groups, for ...soners and psychiatric patients. They have the same problem. They want to stop them from speaking for themselves..."

VI. CONCLUSIONS

Policy Implications for Adult Status

As stated in the introduction, policies concerning disabled persons have been evolving rapidly in the last decade. It has also been pointed out that policies are based on attitudinal models, values and institutional traditions. The last ten years have been significantly marked by a questioning of traditional thinking, especially the medical model, as the valid basis of policy and practice in the field of disability. The questioning of traditional models has been accompanied by the closing down of large institutions and the international spread of the integration of disabled people in mainstream education, employment, leisure and residential living. Besides the economic and political underpinnings of these changes, there has been an increasing concern with the consequence of practices and the latent negative effects of segregative services. This report has tried to pinpoint and illustrate some of the consequences of certain practices, especially those ignoring the developmental and personal needs of disabled clients. The "eternal child" orientation of services has been amply discussed throughout the report.

Evolving policies increasingly emphasize the importance of independence, autonomy, equal opportunities and removing barriers so that disabled people may indeed become participating citizens sharing adult status. Policies may be couched in terms of "equalisation of opportunities", sometimes in terms of "human rights" or "participation" or "removing obstacles". But as the Swedish Minister Lindqvist stated at the OECD Conference in December 1986[54], basing his statement on the World Programme of Action, future definitions of handicap must be based on the perspective of the individual's situation. As has been argued throughout this report, this means going beyond providing services and supports to rehabilitate impairments or provide containment for persons unable to cope; this means concern with the consequences of services for the individual's personal, moral and socio-psychological development. It means being sensitive to problems of identity, self-concept and self-esteem.

During the above Conference, Senator Grimes from Australia called for the importance of creating an environment in which self-esteem and independence could be developed. For this to occur it is not important that risks and challenges be removed, but that strategies be developed to assist disabled young people to cope and make choices, rather than cope and choose for them. He went on to say that negative attitudes on the part of employers and parents lead to a lack of self-esteem that makes it even more difficult to find work for young people with disabilities.

The World Programme of Action concerning disabled persons[55]: The United Nations General Assembly at its 37th session in December 1982 and as a result of the International Year for Disabled Persons declared 1983-1992 as the decade of disabled persons. The main

thrust of the programme is to promote policies and actions that favour the participation of disabled persons and evaluate services from their perspective. Although the goals are couched in general terms, e.g.:

> "The purpose of the World Programme of Action concerning Disabled Persons is to promote effective measures for prevention of disability, rehabilitation and the realisation of the goals of 'full participation' of disabled persons in social life and development of 'equality'.",

specific definitions illustrate the consumer perspective rather than service perspective orientations and care is taken not to simplify the complex individual differences within the disability field:

> "Disabled people do not form a homogeneous group. For example, the mentally ill and the mentally retarded, the visually, hearing and speech impaired, those with restricted mobility or with so-called 'medical disabilities' all encounter different barriers of different kinds, which have to be overcome in different ways. The following definitions are developed from that perspective: ...
>
> - Prevention means measures aimed at preventing the onset of mental, physical and sensory impairments (primary prevention) or at preventing impairment, when it has occurred, from having *negative physical, psychological and social consequences.*
> - Rehabilitation means a *goal-oriented and time-limited process* aimed at enabling an impaired person to reach an optimum mental, physical and/or social functional level, thus providing her or him with the *tools to change her or his own life.* It can involve measures intended to compensate for a loss of function or a functional limitation (for example, technical aids) and other measures intended to facilitate social adjustment or readjustment.
> - Equalisation of opportunities means the process through which the general system of society, such as the physical and cultural environment, housing and transportation, social and health services, educational and work opportunities, cultural and social life, including sports and recreational facilities are made accessible to all."

Included in the consumer perspective of the World Programme of Action is the insistence on the participation of disabled persons and their organisations in the planning of actions, services and legislation.

> "Disabled persons and their organisations should be consulted in the further development of the World Programme of Action and in its implementation. To this end, every effort should be made to encourage the formation of organisations of disabled persons at the local, national, regional and international levels. Their unique expertise, derived from their experience, can make significant contributions to the planning of programmes and services for disabled persons. Through their discussion of issues, they present points of view most widely representative of all concerns of disabled persons. Their impact on public attitudes warrants consultation with them and as a force for change they have significant influence on making disability issues a great priority. The disabled themselves should have a substantive influence in deciding the effectiveness of policies, programmes and services designed for their benefit. Special efforts should be made to involve mentally handicapped persons in the process."

The World Programme of Action urges the implementation of its principles in Member states, stating that it is the ultimate responsibility of National Governments, but local authorities and other bodies within the public and private sector are still called upon to implement national measures.

As a follow-up to the World Programme of Action, Rehabilitation International convened an experts' meeting in Vienna in June 1986 to discuss the role of legislation for the equalisation of opportunities for people with disabilities. The participants were specialists in the legislative process from all regions of the world, and they developed guidelines in three main areas: fundamental legislative and social policy provisions for the equalisation of opportunity, the role of non-governmental organisations in the legislative process and implementation of legislation. The document summarising the meeting is an up-to-date statement concerning "adult status" oriented policies. It is impossible to restitute the contents of this document here. The following are some points significant to the arguments developed in this report.

The discussion on social policy issues was opened by Mr. Bill White, a member of the Status of Disabled Persons Secretariat in Canada. He spoke about present legal reforms in Canada resulting from the new constitution adopted in 1982. The equalisation of opportunities for disabled persons is an essential part of the new constitution and as such the government proposes eleven principles guiding Canada's participation in the Decade of Disabled Persons. Some of these are:

- In the development and implementation of programmes and services every effort shall be made to avoid forcing individuals to leave their families and home communities with the goal of ensuring an early and lasting integration into society of individuals with disabilities;
- There shall be action and public education to minimise environmental factors to remove barriers and remedy social attitudes evolving from ignorance, indifference and fear, which impede the full participation of persons with disabilities;
- Persons with disabilities shall be guaranteed involvement in decision-making which pertains to the design and organisation of programmes and services considered necessary for the integration of disabled persons into all facets of society. In this respect, there shall be particular emphasis on rehabilitation.

Some fundamental provisions which Canada would make in the legislation and equalisation of opportunities would be:

- Use of a functional, rather than a medical, professional approach to the needs of disabled persons;
- See the status of disabled persons very much within the context of rights issues, not health issues;
- Promote change within society wherein the individual is seen as confronting the environment, rather than having to adapt to the environment. This means the removal of environmental barriers to allow for access;
- View the improvement of the status of disabled persons as a citizen's participation issue – participation by disabled persons themselves in the many ways this has been made possible through centres of independent living as well as participation of the total community in awareness and sensitivity to the needs of disabled persons. To implement these principles, the Canadian Government proposes a $16 million fund to advocacy organisations of disabled persons over a period of five years.

Mr. Bengt Lindqvist, Minister for Family Affairs and Matters Concerning the Disabled and Elderly, Sweden, made a statement concerning handicapped rights and social policy. He emphasized the fact that ideas and concepts of equality and full participation for persons with disabilities have been well developed on paper but not in reality. He urged the concrete implementation of fine ideas. To quote him here is an appropriate end to this report:

"For many years we have been concentrating our efforts on the development of individual support in education and rehabilitation. These efforts have, during the last ten years, led us into a new and exciting phase of development. There is now a strong need to analyse the situation of disabled people from the perspective of equal rights and it is necessary to bring into our analysis the actual organisation of the community itself. In a just and decent society, the needs of all citizens are treated on an equal basis. This also means that we have now reached the ultimate stage of integration where the needs of people with disabilities must form an integral part of the general planning of our societies. This does not mean that people with professional knowledge are not needed any longer. On the contrary, it means that we add yet another aspect of our work, an aspect which is absolutely necessary, to realise the basic human rights for people with disabilities. In this future crusade for better conditions, we must all join our forces. But let me add to this that disabled people themselves must take the lead in the struggle, set the goals and formulate the future priorities."[56]

NOTES AND REFERENCES

1. OECD/CERI, *The Integration of the Handicapped in Secondary Schools, Five Case Studies* (November 1985); *Handicapped Youth at Work, Personal Experiences of School-Leavers* (July 1985); *The Transition from School to Working Life* (July 1983); *Integration in the School* (August 1981); *Young People with Handicaps, The Road to Adulthood* (December 1986).
2. "Disability and Restricted Opportunity", OECD Educational Monograph No. 1 (June 1987).
3. Called here a "subject-oriented approach", meaning that the individual's subjective characteristics are also taken into consideration, not only his/her need for services.
4. Comer, R.J. and Piliavin, J.A. (1974), "The Effects of Physical Deviance Upon Face-to-Face Interaction: The Other Side", in *The Handicapped Person in the Community*, ed. D. Boswell, J. Wingrove, Tavistock Publications.
5. Goffman, E. (1963), "Stigma" (p. 6), *Notes on the Management of Spoiled Identity*, Prentice Hall, Inc., Englewood Cliffs, New Jersey.
6. Richardson, S., "The Social Psychological Consequences of Handicapping", quote by M. Hathaway.
7. Goffman, E., *op. cit.*
8. Evans, D.P. (1969), *The Lives of Mentally Retarded People* (p. 137), Westview Press, Boulder, Colorado.
9. Edgerton, R.B. (1967), *The Cloak of Competence*, University of California Press, London, Cambridge.
10. Hayakawa, S.I. (1969), *Language in Action*, University of Toronto Press, New York, Russell Sage Foundation.
11. Scott, R. (1969), *The Making of Blind Men* (p. 119), New York, Russell Sage Foundation.
12. Carling, F. (1980), *And Yet We Are Human* (pp. 47-48), Arno Press, New York.
13. Rees, S. and Emerson, A. (1984), Reports and proceedings No. 37, "Disabled Children, Disabling Practices", Social Welfare Research Centre, University of New South Wales, New South Wales, Australia.
14. *Ibid.*
15. *Ibid.*
16. John, Dr. Mary (1986), "Disabled Young People Living Independently", a paper prepared in collaboration with The British Council of Organisations of Disabled People for the OECD.
17. Söder, M. (1986), "Adult Status for Mentally Retarded Youth", OECD/CERI, Paris.
18. Anderson, Dr. Elizabeth, and Clarke, Lynda (1982), *Disability in Adolescence*, Methuen, London.
19. Carling, F. *op. cit.* (p. 68).
20. Gliedman, J. and Roth, W. (1980), "The Unexpected Minority" (p. 95), *Handicapped Children in America*, Harcourt Brace, Jovanovich, New York.

21. Matthews, G.F. (1983), "Voices from the Shadows", *Women with Disabilities Speak Out*, The Women's Press, Toronto (p. 111).
22. Goffman, E., *op. cit.*
23. Söder, M., *op. cit.*
24. Carling, F., *op. cit.* (p. 65).
25. Counsell, A. (1982), *So Clear in My Mind, An Extraordinary Autobiography of Triumph Over Cerebral Palsy*, Hutchison Press, London (p. 62).
26. *Youth Unemployment* (1978). A Report on the High Level Conference, 15th-16th December 1977, vol. I (pp. 12-13), OECD, Paris.
27. Cohen, S. and Taylor, L. (1978), *Escape Attempts*, Penguin Books, Ltd., England.
28. DHSS (1978), Report of a Seminar on the OPCS Survey, "The Elderly at Home", held on 17th March 1978.
29. Brown, G.W. and Harris, T. (1978), *Social Origins of Depression: A Study of Psychiatric Disorder in Women*, Tavistock Publications, London.
30. Cohen, S. and Taylor, L., *op. cit.*
31. Counsell, A., *op. cit.* (p. 140).
32. Goldstein, J. (1978), "On Being Adult and Being An Adult in Secular Law", in *Adulthood*, edited by Erik H. Erikson, Norton and Company, New York and London.
33. Brakel, S. and Rock, R., "The Mentally Disabled and the Law", in S. Herr, *Rights and Advocacy for Retarded People*, Lexington Books, Toronto, 1983.
34. Goldstein, J., *op. cit.*
35. Rehabilitation Research and Training Center in Mental Retardation, University of Oregon, Eugene, Working Paper No. 69, "Civil Rights of the Mentally Retarded", 1973.
36. Hobbs, N., Cantrell, M.L. and Malloy, B., "An Ecologically-Oriented Service-Based Classification System for the Employment of Handicapped Adolescents", in *The Education of the Handicapped Adolescent: Integration in the School*, OECD/CERI, Paris, 1981.
37. Finkelstein, F. (1980), "Attitudes and Disabled People", World Rehabilitation Fund, Monograph No. 5 (p. 33).
38. Oliver, M. (1983), "Social Work with Disabled People", Practical Social Work Series, BASW (p. 48).
39. McCullough, L.B. (1982), "The World Gained and the World Lost: Labelling the Mentally Retarded", (p. 103), in *Ethics and Mental Retardation*, ed. by Loretta Kopelman and J.C. Moskop, D. Reidel Publishing Company, Dordrecht, Bostob, Lancaster.
40. *Ibid.*
41. DeJong, G. (1979), "The Movement for Independent Living: Origins, Ideology and Implications for Disability Research", University Center for International Rehabilitation, Michigan State University.
42. Heuman, J. (television interview).
43. John, Dr. Mary (1986), "Disabled Young People Living Independently" prepared for the OECD/CERI.
44. *Ibid.*
45. Dybwad, R., "The Retarded Child – The Adult of Tomorrow", in *ILSMH Symposium Proceedings*, 13 (1979).
46. Herr, S.S. (1983), *Rights and Advocacy for Retarded People*, Lexington Books, Lexington, Massachusetts.
47. *Ibid.*

48. "The Genova Challenge" (1986), Technical Report to OECD.

49. Interview with Dr. Enrico Montobbio.

50. Montobbio, E., Botto, G., Calandroni, G. *et al.*, "The Mentally Handicapped: An Adolescent without Adolescence", paper presented at the IXth National Conference of SINPI, San Marino, 1980.

51. *Ibid.*

52. Blom, G.E., M.D. (1985), University Center for International Rehabilitation, Issue Paper: "Heather's Story: Psychotherapy and the Practice of the Least Restrictive Alternative".

53. Söder, M. (1984), *op. cit.*

54. "Active Life for Handicapped Youth", International Conference with Ministerial Participation held at the OECD in Paris, 11th-12th December 1986.

55. The World Programme of Action for Disabled Persons, United Nations, New York.

56. Rehabilitation International Report of the International Expert Meeting on Legislation for Equalisation of Opportunities for People with Disabilities, June 1986, Vienna (p. 70).

WHERE TO OBTAIN OECD PUBLICATIONS
OÙ OBTENIR LES PUBLICATIONS DE L'OCDE

ARGENTINA - ARGENTINE
Carlos Hirsch S.R.L.,
Florida 165, 4º Piso,
(Galeria Guemes) 1333 Buenos Aires
Tel. 33.1787.2391 y 30.7122

AUSTRALIA - AUSTRALIE
D.A. Book (Aust.) Pty. Ltd.
11-13 Station Street (P.O. Box 163)
Mitcham, Vic. 3132 Tel. (03) 873 4411

AUSTRIA - AUTRICHE
OECD Publications and Information Centre,
4 Simrockstrasse,
5300 Bonn (Germany) Tel. (0228) 21.60.45
Gerold & Co., Graben 31, Wien 1 Tel. 52.22.35

BELGIUM - BELGIQUE
Jean de Lannoy,
Avenue du Roi 202
B-1060 Bruxelles Tel. (02) 538.51.69

CANADA
Renouf Publishing Company Ltd/
Éditions Renouf Ltée,
1294 Algoma Road, Ottawa, Ont. K1B 3W8
Tel: (613) 741-4333
Toll Free/Sans Frais:
Ontario, Quebec, Maritimes:
1-800-267-1805
Western Canada, Newfoundland:
1-800-267-1826
Stores/Magasins:
61 rue Sparks St., Ottawa, Ont. K1P 5A6
Tel: (613) 238-8985
211 rue Yonge St., Toronto, Ont. M5B 1M4
Tel: (416) 363-3171
Federal Publications Inc.,
301-303 King St. W.,
Toronto, Ont. M5V 1J5
Tel. (416)581-1552
Les Éditions la Liberté inc.,
3020 Chemin Sainte-Foy,
Sainte-Foy, P.Q. G1X 3V6,
Tel. (418)658-3763

DENMARK - DANEMARK
Munksgaard Export and Subscription Service
35, Nørre Søgade, DK-1370 København K
Tel. +45.1.12.85.70

FINLAND - FINLANDE
Akateeminen Kirjakauppa,
Keskuskatu 1, 00100 Helsinki 10 Tel. 0.12141

FRANCE
OCDE/OECD
Mail Orders/Commandes par correspondance :
2, rue André-Pascal,
75775 Paris Cedex 16
Tel. (1) 45.24.82.00
Bookshop/Librairie : 33, rue Octave-Feuillet
75016 Paris
Tel. (1) 45.24.81.67 or/ou (1) 45.24.81.81
Librairie de l'Université,
12a, rue Nazareth,
13602 Aix-en-Provence Tel. 42.26.18.08

GERMANY - ALLEMAGNE
OECD Publications and Information Centre,
4 Simrockstrasse,
5300 Bonn Tel. (0228) 21.60.45

GREECE - GRÈCE
Librairie Kauffmann,
28, rue du Stade, 105 64 Athens Tel. 322.21.60

HONG KONG
Government Information Services,
Publications (Sales) Office,
Information Services Department
No. 1, Battery Path, Central

ICELAND - ISLANDE
Snæbjörn Jónsson & Co., h.f.,
Hafnarstræti 4 & 9,
P.O.B. 1131 - Reykjavik
Tel. 13133/14281/11936

INDIA - INDE
Oxford Book and Stationery Co.,
Scindia House, New Delhi 110001
Tel. 331.5896/5308
17 Park St., Calcutta 700016 Tel. 240832

INDONESIA - INDONÉSIE
Pdii-Lipi, P.O. Box 3065/JKT Jakarta
Tel. 583467

IRELAND - IRLANDE
TDC Publishers - Library Suppliers,
12 North Frederick Street, Dublin 1
Tel. 744835-749677

ITALY - ITALIE
Libreria Commissionaria Sansoni,
Via Lamarmora 45, 50121 Firenze
Tel. 579751/584468
Via Bartolini 29, 20155 Milano Tel. 365083
La diffusione delle pubblicazioni OCSE viene assicurata dalle principali librerie ed anche da :
Editrice e Libreria Herder,
Piazza Montecitorio 120, 00186 Roma
Tel. 6794628
Libreria Hœpli,
Via Hœpli 5, 20121 Milano Tel. 865446
Libreria Scientifica
Dott. Lucio de Biasio "Aeiou"
Via Meravigli 16, 20123 Milano Tel. 807679

JAPAN - JAPON
OECD Publications and Information Centre,
Landic Akasaka Bldg., 2-3-4 Akasaka,
Minato-ku, Tokyo 107 Tel. 586.2016

KOREA - CORÉE
Kyobo Book Centre Co. Ltd.
P.O.Box: Kwang Hwa Moon 1658,
Seoul Tel. (REP) 730.78.91

LEBANON - LIBAN
Documenta Scientifica/Redico,
Edison Building, Bliss St.,
P.O.B. 5641, Beirut Tel. 354429-344425

MALAYSIA/SINGAPORE - MALAISIE/SINGAPOUR
University of Malaya Co-operative Bookshop Ltd.,
7 Lrg 51A/227A, Petaling Jaya
Malaysia Tel. 7565000/7565425
Information Publications Pte Ltd
Pei-Fu Industrial Building,
24 New Industrial Road No. 02-06
Singapore 1953 Tel. 2831786, 2831798

NETHERLANDS - PAYS-BAS
SDU Uitgeverij
Christoffel Plantijnstraat 2
Postbus 20014
2500 EA's-Gravenhage Tel. 070-789911
Voor bestellingen: Tel. 070-789880

NEW ZEALAND - NOUVELLE-ZÉLANDE
Government Printing Office Bookshops:
Auckland: Retail Bookshop, 25 Rutland Street,
Mail Orders, 85 Beach Road
Private Bag C.P.O.
Hamilton: Retail: Ward Street,
Mail Orders, P.O. Box 857
Wellington: Retail, Mulgrave Street, (Head Office)
Cubacade World Trade Centre,
Mail Orders, Private Bag
Christchurch: Retail, 159 Hereford Street,
Mail Orders, Private Bag
Dunedin: Retail, Princes Street,
Mail Orders, P.O. Box 1104

NORWAY - NORVÈGE
Narvesen Info Center - NIC,
Bertrand Narvesens vei 2,
P.O.B. 6125 Etterstad, 0602 Oslo 6
Tel. (02) 67.83.10, (02) 68.40.20

PAKISTAN
Mirza Book Agency
65 Shahrah Quaid-E-Azam, Lahore 3 Tel. 66839

PHILIPPINES
J.J. Sagun Enterprises, Inc.
P.O. Box 4322 CPO Manila
Tel. 695-1946, 922-9495

PORTUGAL
Livraria Portugal,
Rua do Carmo 70-74,
1117 Lisboa Codex Tel. 360582/3

SINGAPORE/MALAYSIA - SINGAPOUR/MALAISIE
See "Malaysia/Singapor". Voir « Malaisie/Singapour »

SPAIN - ESPAGNE
Mundi-Prensa Libros, S.A.,
Castelló 37, Apartado 1223, Madrid-28001
Tel. 431.33.99
Libreria Bosch, Ronda Universidad 11,
Barcelona 7 Tel. 317.53.08/317.53.58

SWEDEN - SUÈDE
AB CE Fritzes Kungl. Hovbokhandel,
Box 16356, S 103 27 STH,
Regeringsgatan 12,
DS Stockholm Tel. (08) 23.89.00
Subscription Agency/Abonnements:
Wennergren-Williams AB,
Box 30004, S104 25 Stockholm Tel. (08)54.12.00

SWITZERLAND - SUISSE
OECD Publications and Information Centre,
4 Simrockstrasse,
5300 Bonn (Germany) Tel. (0228) 21.60.45
Librairie Payot,
6 rue Grenus, 1211 Genève 11
Tel. (022) 31.89.50
United Nations Bookshop/Librairie des Nations-Unies
Palais des Nations,
1211 - Geneva 10
Tel. 022-34-60-11 (ext. 48 72)

TAIWAN - FORMOSE
Good Faith Worldwide Int'l Co., Ltd.
9th floor, No. 118, Sec.2
Chung Hsiao E. Road
Taipei Tel. 391.7396/391.7397

THAILAND - THAILANDE
Suksit Siam Co., Ltd., 1715 Rama IV Rd.,
Samyam Bangkok 5 Tel. 2511630

INDEX Book Promotion & Service Ltd.
59/6 Soi Lang Suan, Ploenchit Road
Patjumamwan, Bangkok 10500
Tel. 250-1919, 252-1066

TURKEY - TURQUIE
Kültur Yayinlari Is-Türk Ltd. Sti.
Atatürk Bulvari No: 191/Kat. 21
Kavaklidere/Ankara Tel. 25.07.60
Dolmabahce Cad. No: 29
Besiktas/Istanbul Tel. 160.71.88

UNITED KINGDOM - ROYAUME-UNI
H.M. Stationery Office,
Postal orders only: (01)211-5656
P.O.B. 276, London SW8 5DT
Telephone orders: (01) 622.3316, or
Personal callers:
49 High Holborn, London WC1V 6HB
Branches at: Belfast, Birmingham, Bristol, Edinburgh, Manchester

UNITED STATES - ÉTATS-UNIS
OECD Publications and Information Centre,
2001 L Street, N.W., Suite 700,
Washington, D.C. 20036 - 4095
Tel. (202) 785.6323

VENEZUELA
Libreria del Este,
Avda F. Miranda 52, Aptdo. 60337,
Edificio Galipan, Caracas 106
Tel. 951.17.05/951.23.07/951.12.97

YUGOSLAVIA - YOUGOSLAVIE
Jugoslovenska Knjiga, Knez Mihajlova 2,
P.O.B. 36, Beograd Tel. 621.992

Orders and inquiries from countries where Distributors have not yet been appointed should be sent to:
OECD, Publications Service, 2, rue André-Pascal, 75775 PARIS CEDEX 16.

Les commandes provenant de pays où l'OCDE n'a pas encore désigné de distributeur doivent être adressées à :
OCDE, Service des Publications 2, rue André-Pascal, 75775 PARIS CEDEX 16.

71784-07-1988

OECD PUBLICATIONS, 2, rue André-Pascal, 75775 PARIS CEDEX 16 - No. 44531 1988
PRINTED IN FRANCE
(96 88 02 1) ISBN 92-64-13132-9